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UNIVERSITY OF ALBERTA

The Aftermath of SIDS: Questioning the Research

by

Karen Martin

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A Thesis

Submitted to the Faculty of Graduate Studies and
Research in partial fulfilment of the requirements
for the degree of
MASTER OF ARTS

DEPARTMENT OF SOCIOLOGY

Edmonton, Alberta

FALL, 1993

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Karen Martin

Karen K. Martin
6803 111 Street
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Date: October 5, 1993

Ben: You're not the only one who lost a child, Lily. So did I! So did I! And that pain is going to stay with me the rest of my life. Jimmy is dead. Jimmy is dead, God damn it. And you can't bring him back by turning this house into a graveyard. He's dead, damn it. But I'm alive. I'm alive and I'm not going to pretend to be dead anymore just to keep you company …

Lily: I heard him cry. I heard him crying and I didn't go. I never could tell you. I could never tell anybody. I was, I was sewing and I heard him cry just once and I waited and he didn't make another sound and so I kept on sewing and when I went in to get him from his nap, he was, he was dead and I, if, if I'd gone, … he wouldn't be dead. I can't stand to be touched. I can't stand to feel anything. All I can stand is to just be numb inside and to be sorry every single minute because when I'm not, I hear his crying in my head, over and over and over.

Ben: It's not your fault, Lily. Nobody can answer every little cry.

Lily: It doesn't matter. Not a minute goes by that I don't hear his cry in my head.

Ben: I can't help you, can I Lily? I can't go on living like this. I'm leaving.

Dialogue from Kroopf, S. & Palmer, P. (Producers), & Donoghue, M. A. (Director). (1991). **Paradise** [video]. Touchwood.

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE AFTERMATH OF SIDS: QUESTIONING THE RESEARCH submitted by KAREN MARTIN in partial fulfilment of the requirements for the degree of MASTER OF ARTS.

Dr. L. Larson, Supervisor

Dr. S. Kent, Committee Member

Dr. P. A. Field, Committee Member

Date: April 16, 1993

Dedication

To all the little boys and little girls stolen by SIDS and to all their parents and brothers and sisters and grandparents.

Abstract

Each year close to four hundred Canadian families lose an infant to Sudden Infant Death Syndrome (Statistics Canada, 1987a), also known as SIDS or crib death. SIDS is defined as:

> the sudden death of an infant, usually between two weeks and 1 year of age, occurring during sleep, that is unexpected from the medical history and that remains unexplained after review of the circumstances surrounding death and a complete examination, including autopsy, by a qualified pathologist (Franciosi, 1983, p. 332).

Despite an international research effort, the cause of SIDS is still unknown, leaving parents with no explanation for the sudden and unexpected death of their baby.

This study, however, is not about the search for the cause of SIDS. Instead it is about the aftermath of SIDS, that is, what it is like to lose a baby to SIDS. Rather than generating new information about this experience, this study examines and critiques sociological, psychological, and medical research to see what is currently known about the SIDS aftermath. Then it examines and challenges the research methodology used for these studies. The thesis concludes with a list of specific research questions and with recommendations for a qualitative research design for future studies.

Acknowledgments

There are so many people to thank. I could not have done this study without your kind support and love.

Thank you to the members of the Board of Consultants of the Canadian Foundation for the Study of Infant Deaths (CFSID) for agreeing to fund this study. Thank you for seeing its merit and going out on a limb.

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Thank you to the original members of my thesis committee: Dr. Larson, Dr. Kent, and Dr. Morse. You each gave me something special. Dr. Larson, thank you for your continual support and respect for my work; Dr. Kent, thank you for your continual enthusiasm and excitement about my findings; and Dr. Morse, thank you for your continual challenges and for sharing your knowledge about qualitative research. Thank you also to Dr. Field who took Dr. Morse's place when she left to go to another university. Dr Field, I appreciate your willingness to be involved so late in the process and the many ways you bolstered my confidence in my findings.

A special thank you to my family, particularly my husband who helped me in so many ways, first by just believing in me and then encouraging me every step of the way, and secondly by doing everything you could to help me win my fight with computers. Thank you also to each member of my family and all my special friends for understanding my obsession with this project and doing what you could to help.

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Chapter 1
Introduction

Defining SIDS

Every year nearly four hundred Canadian families[1] lose their babies to an "unpredictable, unpreventable, and unexplainable" (Valdes–Dapena, 1991, p. 11) killer. Although this killer is "as old as humankind," it had no formal name or definition until 1969 (Valdes-Dapena, 1991, p. 3). Although it has had other names in the past, now we call it Sudden Infant Death Syndrome, SIDS, or crib death. SIDS is currently defined as:

> the sudden death of an infant, usually between two weeks and 1 year of age, occurring during sleep, that is unexpected from the medical history and that remains unexplained after review of the circumstances surrounding death and a complete examination, including autopsy, by a qualified pathologist (Franciosi, 1983, p. 332).

The World Health Organization did not recognize SIDS as "a distinct and official cause of death" until 1979 (Valdes-Dapena, 1991, p. 11). Despite a tremendous world-wide search for the cause of this syndrome, it continues to be a medical mystery and it continues to take the lives of apparently healthy babies all over the world.

Diagnosing SIDS

Because the cause of SIDS is still unknown and because babies die suddenly and mysteriously for other reasons too, the diagnosis of

---

[1] According to Statistics Canada, 392 babies died of SIDS in 1987 (Statistics Canada, 1989a).

SIDS is not easily and hastily made. In fact, the diagnostic process itself is quite complex. The police are almost always involved because it is their job to investigate all sudden and unexplained deaths. They begin their investigation by first noting the circumstances of the death. Then they examine the baby and scene of death for evidence of "accidents and child battering" (Valeriote & Fine, 1987, p. 202). They also question the parents or person responsible for the care of the baby. If the police can rule out physical harm as the possible cause of death, then they turn the investigation over to the coroner or the medical examiner's office.

Using an autopsy as the primary investigative tool, the coroner or medical examiner examines the body for signs of previously undetected abuse, congenital problems, and signs of illnesses. If there is no indication of a problem "sufficient to cause death" (Hillman, 1991, p. 23) and all other circumstances of the death meet the diagnostic definition for SIDS, then SIDS can be certified as the official cause of death. This diagnosis does not explain how or why the baby died, however; it merely eliminate or excludes all other reasonable explanations (Zielke et al., 1989). It also gives the mysterious killer a name.

But just having a name for the syndrome that killed their baby does not necessarily ease the parents' pain and put their mind at ease. Nevertheless, many legal and medical authorities, family doctors, ministers, and others assume that this diagnosis should answer the parents' questions about why their baby died. People expect parents to accept the diagnosis, grieve the loss of their baby, and, within a relatively short period of time, get on with their lives. But many parents cannot believe that their apparently healthy baby could die for no reason at all. It makes no sense to them.

As long as the actual cause of SIDS remains a mystery, many grieving parents will continue their own secret inquiry into their baby's death (Fetus and Newborn Committee, 1983). Although they are often aware of the irrationality of their thoughts, parents often struggle with the fear that they may have, inadvertently, done something to cause their baby to die. Guilt and a nagging sense of responsibility may seriously complicate the parental grief process, a process that may last for years.

Defining the Research Problem

For many years researchers paid little attention to the impact of a SIDS death on the surviving parents and siblings. Instead, researchers focused their energies on the search for the cause of SIDS. Then, in 1969, Bergman, Pomeroy, and Beckwith published one of the first articles about the problems of families who had lost a baby to SIDS. Entitled "*The Psychiatric Toll of the Sudden Infant Death Syndrome*", the article reports on the authors' observations and interviews with 225 families. Since the publication of this article, many other researchers have explored various facets of this unique and devastating grief experience. But is this research really capturing an accurate picture of the parents' experiences over the full length of time it takes them to deal with their baby's death? It is time someone looked closely at this research. It is time someone questioned the findings and the methodology behind the studies. That is the problem guiding this study.

Defining the Study's Purpose and Rationale

The purpose of this study is to carefully and critically examine a large body of research about the SIDS grief experience in order to answer the following questions:

- What does the research say about what it is like for parents and siblings to lose a baby to SIDS?
- Is this research consistent, conclusive, and valid?
- What research methodologies were used to provide us with this information and are these methods appropriate for the subject matter?
- What questions about this experience remain either unanswered or poorly answered?
- What methodology best suites this research subject?

The results of this study can be used to guide the design and implementation of further research about the psychological aftermath of losing a baby to SIDS.

Overview

In Chapter Two, I review what is currently known about SIDS from the medical literature. I begin Chapter Three by introducing the topic of parental grief and then I identify four unique circumstances of a SIDS death that interact to increase the trauma of the death and to produce a specific kind of parental grief. I examine and critique a large body of research about parental grief. Specifically, I look at the following issues: the parents' early individual reactions, parental guilt, gender differences, the impact this loss has on marital relationships and the other children, and, lastly, the changing nature of parental grief over time. Throughout this review, I reveal the unanswered questions and challenge the findings that seem poorly formulated. In Chapter Four, I examine and question some of the methodology used to gather what we know about this tragic experience. In my critique I look at the positions researchers took when they studied parental grief, what research instruments they used, the nature of the samples they studied, what period of grief they studied, and how they analyzed their data. In the final chapter, I provide a list of specific research questions and then I discuss the most appropriate research methodology to address this most sensitive and personal subject.

Chapter 2
The Search for the Cause of SIDS

Medical Research

In his 1988 review of the history of the search for the cause of SIDS, Krous mentions two early theories that implied direct and unmistakable parental responsibility for the death of babies: overlaying and infanticide. Overlaying occurred when someone accidentally lay on the baby in bed and smothered it with his or her body. The Bible contains the earliest recorded reference to overlaying: "And this woman's child died in the night; because she overlaid it" (1 Kings 3:19). The Catholic Church treated overlaying as a sin for centuries, but the penance was less severe than for intentional murder. Eventually, to prevent overlaying, a structure called an arcutio was constructed in Italy. The arcutio looked like a cage with holes on either side to allow breast feeding. The bars across the top prevented anyone from accidentally laying on top of the baby.

Not all doctors treated overlaying as purely accidental, however. In 1892, a Scottish forensic pathologist named Dr. Templeman described 258 infant deaths attributed to overlaying (Krous, 1988; Valdes-Dapena, 1991). He noted some important features of these deaths: "male predominance [and] higher wintertime incidence" (Krous, 1988, p. 19) and the highest incidence in babies aged one to six months of age (Valdes-Dapena, 1991). Templeman's description of his pathologic findings coincides with modern findings in babies known to have died of SIDS. Unfortunately for the families who had to deal with him, this doctor still assumed that overlaying had caused these babies to die. He believed, therefore, that these deaths were preventable. He adamantly blamed the parents for living in overcrowded homes and for being drunk and ignorant. To prevent the deaths of healthy babies in the future, he recommended that parents be forbidden to sleep with their infants.

Other pathologists believed that actual infanticide was the most likely cause of death. Krous notes that "as recently as November 1984, a British Home Office pathologist was of the opinion that most cases of SIDS were caused by parents smothering their infants" (1988, p. 19). This pathologist clearly blamed the parents; one can only wonder what effect this accusation would have on innocent parents. To this day, however, child battery or infanticide by other means must still be ruled out as the possible cause of the sudden death of an apparently healthy baby.

Researchers in the 1600's developed a new theory that eliminated parental responsibility altogether. Instead it focused on possible problems with the baby's physiology: one theory in particular postulated that an enlarged thymus blocked the functioning of the baby's heart and blood vessels (Mandell, 1988). This theory was not fully discredited until 1931 (Krous, 1988). Next came the belief that the babies had died because of accidental suffocation. Suffocation was not discounted as a reasonable explanation until the 1950's, but, because there was no other explanation to take its place, doctors continued to list suffocation as the cause of death on death certificates for some time after that.

It was not until 1969 that SIDS was finally recognized as an identifiable and unique syndrome. Still, however, the diagnosis of SIDS remained "necessarily a diagnosis of exclusion" (Bergman, Beckwith, & Ray, 1969, p. 17). Although now the syndrome had a name, researchers still did not know what caused it. And over the years, researchers have examined many possible causes. Kelly & Shannon (1982) reviewed many epidemiological, genetic, pathological, metabolic, and physiological research articles about the possible cause of SIDS reported between 1964 to 1982. I have further summarized their findings and then added a few studies reported since 1982.

Reporting on the work of epidemiologists, Kelly & Shannon (1982) listed environmental factors that seem connected with an increased incidence of SIDS: low socioeconomic status of parents; mothers under 20 years of age; unmarried mothers; mothers with poor prenatal care, illness during pregnancy, short interpregnancy intervals, or previous fetal loss; and mothers who either smoked or used narcotics. Researchers also found an ethnic difference: Native Indians have the highest rate of SIDS while Oriental families have the lowest

rate. Male children seem to be at slightly more risk than female babies.[2] In her review of the research, Hillman (1991) suggests that there appears to be a SIDS season, that is, a time of year when more babies die of SIDS. Using statistics from the Chief Medical Examiner's Office in Alberta, Figure One on page 8 shows that the season for SIDS in Alberta is in the fall and early winter. Valdes-Dapena (1991) says that the incidence of SIDS always rises all over the world during the winter months. When the seasons are not distinct, the fluctuations in incidence are less noticeable.

None of the epidemiological factors actually help us to predict a SIDS death or to prevent it. In fact, most babies who die of SIDS do not fit the high-risk profile. According to Hillman (1991), most families who lose babies to SIDS are actually in the low-risk group: women who are middle class and in their mid-twenties, women who have done everything possible to make sure both they and their baby are healthy during pregnancy and after birth. This fact adds to the mystery we call SIDS. And so the search continues for an explanation

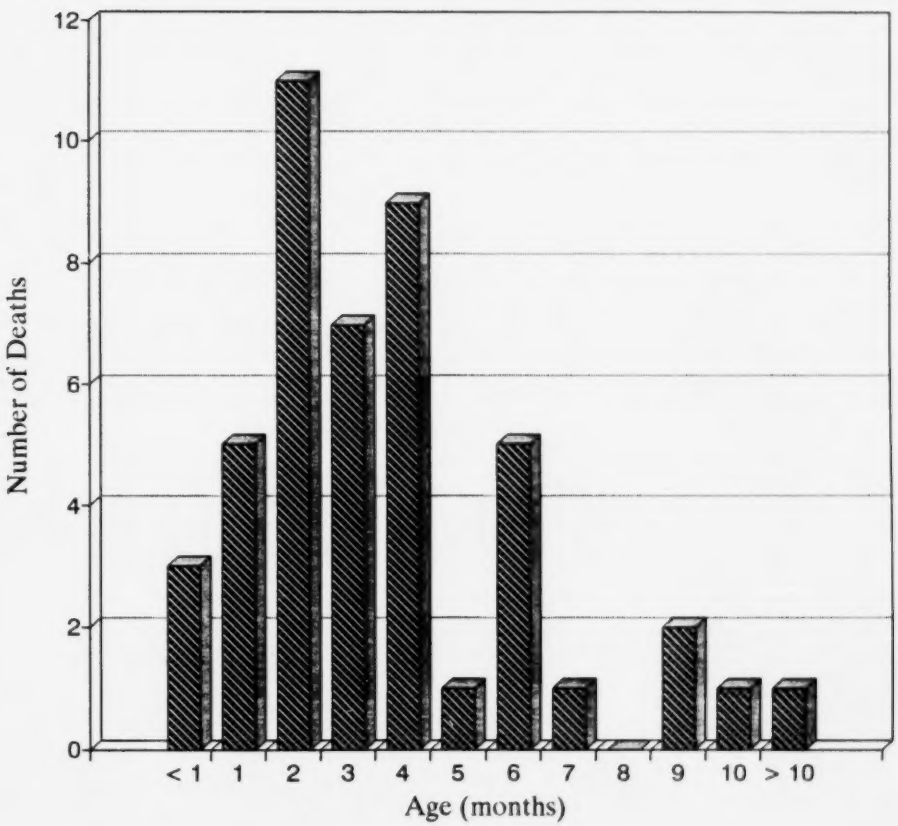
Although there is a higher rate of SIDS amongst multiple births than singletons, this likely has more to do with birth weight than any genetic connection (Valdes-Dapena, 1991). Kelly & Shannon (1982) report that research into a genetic component to SIDS has not been fruitful at all.

According to their review of the literature, Kelly & Shannon (1982) found that pathological investigations have revealed a deficiency in the oxygen supply to various parts of the baby's body. Studies of the existence of possible infections showed that infants who died of SIDS often had upper respiratory infections within days of their death. But then many babies that do not die of SIDS also get these same infections.

---

[2] In 1987 254 boys and 138 girls died of SIDS in Canada (Statistics Canada, 1989a). The incidence of SIDS is much higher in boys (132.1/100,000 population) than in girls (75.9/100,000 population) (Statistics Canada, 1989b) nationally. According to a informal report (1993) from Office of the Chief Medical Examiner in Alberta, an equal number of boys (23) and girls (23) died of SIDS in Alberta in 1992.

Figure One: Incidence of SIDS
Alberta 1992, by Baby's Age (n=46)



Metabolic studies found that children born to methadone-addicted mothers were at a high risk for SIDS (Kelly & Shannon, 1982). Methadone was not found in the child's body on autopsy. Children born to mothers who smoked were at a greater risk than those whose mothers did not smoke (Kelly & Shannon, 1982; Valdes-Dapena, 1991; Hillman, 1991). Once more, however, babies living in non-smoking households also die of SIDS.

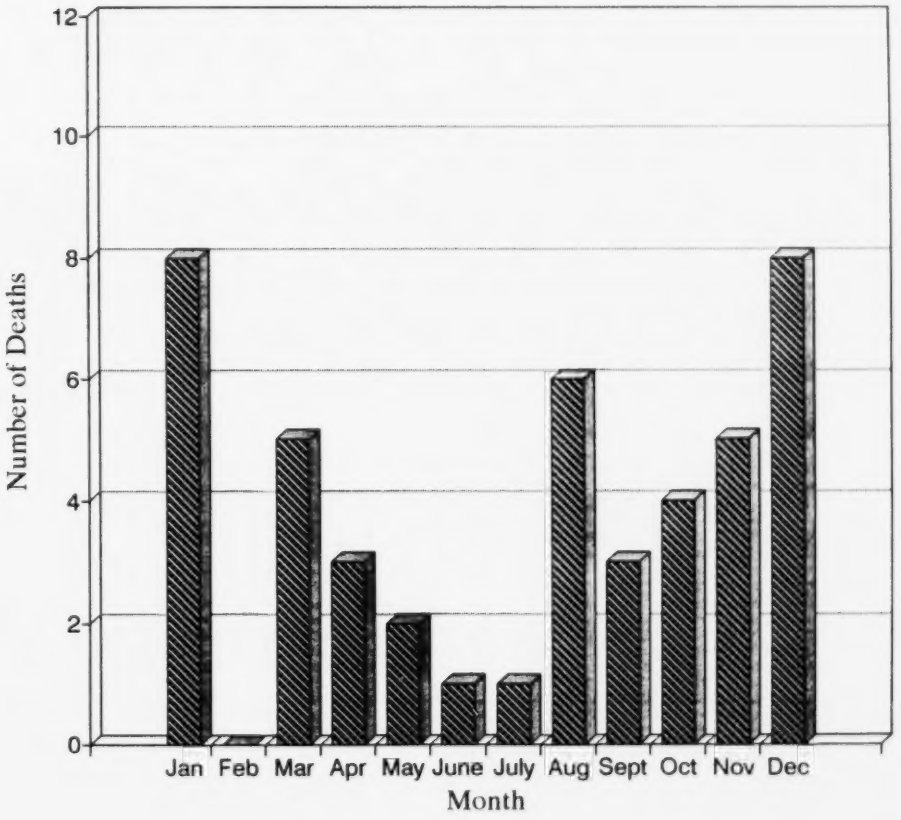
By studying the physiology of SIDS babies, researchers have found that some of these babies had abnormal heart rates and problems with breathing during sleep (Kelly & Shannon, 1982). Although researchers have not reached any solid conclusions about this, there seems to be a growing interest in the theory that babies who eventually die of SIDS may have had a lethal but currently undetectable developmental problem (Valdes-Dapena, 1991) related to breathing. The fact that the greatest proportion of babies die of SIDS between the ages of two and four months old may add credence to the theory (Valdes-Dapena, 1991; Hillman, 1991). Using data from an informal report from the Chief Medical Examiner's Office in Alberta, Figure Two on page 10 shows that the incidence of SIDS in babies of varying ages during 1992.

My review of more recent medical journals shows that researchers are investigating possible connections between SIDS and a number of problems with the baby's health: low birth weight (Grether & Schulman, 1989); genetic enzyme deficiencies (Burchell et al., 1989); bacterial toxins (Newbold et al., 1989); and abnormal haemoglobin levels (Zielke et al., 1989). The **Second SIDS Family International Conference Program and Abstract Booklet** (February 1992) lists ninety-five presentations about research into possible factors and causes. At the end of the conference, however, researchers seemed to come to only one solid and undeniable conclusion: the cause of SIDS remains a mystery.

Medical Research and the Media

Meanwhile the popular press reports each new theory as it surfaces. While this is important when research is credible, the press also reports theories put forth by people with no medical knowledge at

Figure Two: Incidence of SIDS
Alberta 1992, by Month (n=46)



all. An outrageous example comes from a newspaper in British Columbia ("Baby's breath in peril," 1992). The article quotes a British architect who believed SIDS might be caused by "parents' well-meaning efforts" to "completely redecorate the room: new crib, new mattress, new paint, new wallpaper, new carpet, new stuffed toys" (p. C1). Any newly bereaved parent who read this article and these words in particular: "hidden chemicals endanger their baby with every breath (p. C1)" would quickly feel responsible for his or her baby's death. After all, what parent has not put at least one new thing into the baby's room? This kind of irresponsible journalism can only hurt parents who have already lost their babies.

Medical Research, Media Reports, and Parental Reactions

Even when the media reports credible research, parents who have already lost babies to SIDS may feel guilty. The Seattle Times printed an editorial written by two researchers from the University of Washington School of Medicine (Guntheroth & Spiers, 1991). These doctors discussed recent evidence that correlated side or back sleeping positions for babies with a reduced risk for the incidence of SIDS. Very soon thereafter, the newspaper published a letter from a mother whose baby had died while in the prone position. Her sad letter prompted another doctor to write to the editor as well, trying to explain that: "[p]arents may not appreciate the very preliminary nature of this new information and unnecessarily feel guilt and remorse" (Morse, August 25, 1991). This example points to the problem with sharing possible breakthroughs in SIDS research: Those who have already lost their babies may use new information to support their long-held belief that they were, in fact, responsible for their baby's death.

This is the very problem that might deter the implementation of programs such as the "Reduce the Risks" campaign being tried in New Zealand, the county of Avon in England, and in some Australian states. A pamphlet from the Australian Sudden Infant Death Research Foundation says:

> Until more is known abut SIDS, the best way to protect individual babies is to try to reduce the risks we know exist. This brochure shares information about SIDS and suggests ways in which parents can minimize the risks to their babies. Suggestions are based on

> research findings, some of which are recent and, as yet, not proven fact (Reducing the Risks of Cot Death [pamphlet], no date, p. 2).

The brochure lists four ways to "reduce the risk" of SIDS. You will note that no one is saying that this is how to prevent SIDS.

- Sleep your baby on his or her side or back.
- Do not let your baby get too hot.
- Keep your baby in a smoke-free environment during pregnancy and for at least the first year after birth.
- Feed your baby breast milk if possible.

Just reading this pamphlet or hearing these suggestions might make parents who have already lost babies to SIDS feel guilty. But, if this type of campaign really reduces the incidence of SIDS - and such claims were being made at the recent international conference in Australia - should SIDS organizations everywhere be adopting such programs, despite the impact on those who have already lost babies to SIDS? This question is bound to spark debate among members of SIDS groups and SIDS foundations around the world. In the meantime, the search for the cause of SIDS continues while babies die and families grieve.

Chapter 3
Questioning the SIDS Aftermath Research

Introduction

When a loved one dies, people experience varying degrees of emotional, physical, intellectual, spiritual, and interpersonal pain. We call this pain grief (Dershimer, 1990; Simos, 1979; Walsh & McGoldrick, 1991; Worden, 1982). Dealing with one's grief means going through a process of gradually learning to live with a loss, integrating it into one's life, and deriving some kind of meaning from it (Arnold & Gemma, 1991). Learning to deal with grief is hard work, but the grief that comes from the death of a child seems particularly difficult to bear.

Parental grief is difficult and painful no matter what causes the child's death and no matter how old the child is at the time of death (Arnold & Gemma, 1991; Bolton, 1986; Day & Hooks, 1987; DeFrain, Taylor, & Ernst, 1982; Feeley & Gottlieb, 1988; Hutchins, 1986; Klass, 1988; Klass & Marwit, 1988; Knapp, 1986; Kupst, 1986; Lietar, 1986; Nichols, 1986; Rando, 1986a, 1986c; Sanders, 1986; Schmidt, 1986; Simos, 1979; Smith & Borgers, 1988; Worden, 1982). Research shows that the death of a child causes a "more intense grief reaction" than the death of either a spouse or a parent (Sanders, 1980, p. 309).

Because "the sense of selfhood involved in parenting is a central part of [people's] being" (Klass, 1988, p. 4), the death of a child makes parents feel like they have lost a part of themselves. Rando (1986b) suggests that parents think of their children as "an extension of ourselves" and that parents "invest [their children] with a myriad of meanings, along with parental hopes, dreams, needs, and wishes for immortality" (p. 49). In fact, for many people, children symbolize a

commitment to life itself. As George Bernard Shaw once wrote, "Life is a flame that is always burning itself out, but it catches fire again every time a child born."[3]

When an infant dies within the first year of life, the grief is especially difficult to bear. The death of an infant to SIDS, however, triggers the most severe parental grief reaction. These parents experience significantly more intense early grief and more anxiety, anger, self–reproach, restlessness, sleep disturbances, and intrusive thoughts than parents who lose their infant to either stillbirth or neonatal death (Dyregrov & Matthiesen, 1987b). Losing a baby to SIDS triggers the "most severe crisis [parents] have experienced in their lifetime" (DeFrain & Ernst, 1978, p. 987). Parents must find a way to endure the pain it may cause them for the rest of their lives (Arnold & Gemma, 1991; DeFrain, Ernst, Jakub, & Taylor, 1991; Rubin, 1985). Some may never recover from this tragic experience (DeFrain et al., 1991).

What follows is a detailed and thorough examination of what researchers currently understand about the nature of this experience. I begin with a look at the unique circumstances surrounding a SIDS death and how these circumstances interact to increase the intensity of parental grief. Then I examine studies that attempt to describe and explain aspects of parental grief and, to a lesser degree, sibling grief. As I proceed, I look for support for some of the findings, challenge the validity of some findings, and identify important issues that could be addressed in future studies.

The Unique Circumstances of a SIDS Death

Markusen, Owen, Fulton, & Bendiksen (1978) suggest that family members left behind after a baby dies of SIDS are the living "victims" (p. 277) of the syndrome. These victims often suffer a traumatic and problematic "aftermath" (p. 277). To understand why this

[3] From Wallis (1965), **The Treasure Chest**, p. 53.

grief is so difficult, Markusen et al. reviewed studies published between 1944 and 1975. Using their review as my foundation, I looked at more recent studies and reexamined some of the studies they reviewed. Like Markusen et al., I found support for four unique circumstances of the death that may contribute to intense parental grief reactions: SIDS takes the lives of infants; SIDS occurs suddenly and without warning; sudden and unexpected deaths must be investigated; and the cause of SIDS is unknown.

SIDS takes the lives of infants

"The complex grief parents experience after the death of a child is in a sense a continuation of the complex dynamics by which attachment of the child was created and developed" (Klass & Marwit, 1988, p. 31). The more central the attachment, the more intense the grief reaction (Bugen, 1983; Worden, 1982). Therefore, to understand parental grief, it is important to first understand the "complex dynamics" of the parent-infant relationship before the baby died. I track the history of this attachment from before the baby is even conceived to the early months of life.

The pre-birth relationship

With the arrival of effective family planning methods, most women can decide if and when they want to have a child. Consequently, a woman may begin a "pre–birth relationship" (Stainton, 1985, p. 325) with her baby either when she first "conceives of" the idea of becoming pregnant (Winnicott, 1987a, p. 51) or when she begins to plan a specific pregnancy (Peppers, 1987). With confirmation of a wanted pregnancy, a "mysterious union" (Bergum, 1986, p. 96) between mother and baby begins and intensifies over time. As the months pass and the baby makes its presence felt, "child and woman are truly one body," creating a setting for an "intimate relationship that no one else [can] share" (Bergum, 1989, p. 58).

First pregnancies change women's identities, transforming them from women into mothers (Bergum, 1989). The "social process of identity construction" (Lovell, 1983, p. 760) occurs through the interaction of physical and emotional changes, the way others treat women when they are pregnant, and the experience of giving birth (Bergum, 1989; Lovell, 1983). Writing about her own experiences during pregnancy, Jackson (1992) says that, for women,

> pregnancy ends the illusion of autonomy. You are housing somebody else, a living presence. ... It's a third party to the relationship long before the father suspects. He may sing to the baby and converse with your belly, but it's just an idea, until the baby is born. For a woman, it's already the root, the core around which she walks and dreams (p. 35).

Research confirms that, as Jackson (1992) suggests, men's relationships with their unborn children are more distant. Most men do not "define [themselves] as a father and the world around [them] in terms of [their] future fatherhood" (May, 1982, p. 341) until about the twenty–sixth week of an actual pregnancy. This redefinition of self during the last trimester of the pregnancy occurs as expectant fathers begin to feel intellectually connected to their baby (May, 1979, 1982; Smith, 1983; Peppers & Knapp, 1980). Peppers and Knapp (1980) contend that unlike mothers, fathers may not bond with their baby until it is born. On a practical note, perhaps many first–time fathers have difficulty connecting to or even imagining their baby any earlier because they have little experience caring for babies (Lewis, 1982; Soule, Standley, & Copans, 1979).

Before the baby's birth, expectant fathers can choose the degree to which they will be involved (Brazelton & Cramer, 1990). Even after making a commitment to their unborn baby and beginning to think of themselves as fathers, some men do not show their "sense of fatherliness" (Soule, Standley, & Copans, 1979, p. 261) by becoming emotionally involved with the pregnancy. Instead they increase their commitment to their jobs or careers during the latter months of the pregnancy (Brown, 1987). May (1980) found three distinct styles of father involvement during pregnancy. "Observer" expectant fathers act

like "bystanders" (p. 449), investing little emotional energy in the pregnancy or their unborn child. In contrast, men who adopt an "expressive style" become emotionally involved with the pregnancy; they consider themselves "full partner[s]" in the experience. Men who assume the "instrumental" style act like a "caretaker or manager of the pregnancy." Although interested in making sure the pregnancy goes well, these men do not connect to the baby on an emotional level.

The parent–infant relationship

Both before and after a baby is born, family members begin "making [a] place" (Bright, 1992, p. 86) physically and socially. Bright calls the preparation of the baby's spot in the house "nesting" (p. 86). Social space–making includes: naming the baby, attributing the baby's characteristics to others in the family, and welcoming the baby by giving gifts, speaking to or about the baby, and interacting with the baby. While Bright studied how parents and grandparents make a place for a first born child, this concept seems equally applicable to families welcoming their next child as well. The point is that the arrival of a baby changes the family; everyone must learn to make room.

Parents are also forced to make time for their baby as well. Babies require constant and continuous care and attention. "What makes the transition to parenthood so unique, and for some parents especially frustrating, is the amount of attention that infants require" (LaRossa, 1986, p. 88). Because the need for attention is continuous, parental involvement must also be continuous.[4] Someone must always be "on duty" (p. 90), particularly for the early years of a child's life.

Because mothers usually assume about ninety percent of this responsibility (LaRossa, 1988), they have many opportunities to interact

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[4] Parental involvement can be divided into three components: engagement ("time spent in one-to-one interaction with a child"); accessibility (time spent being in "a less intense degree of interaction" in which the parent may be available to the child but is not focused specifically on the child); and responsibility (time spent physically and mentally "being accountable for the child's welfare and care") (Lamb (1987), cited in LaRossa, 1988, p. 452).

with the baby. The seemingly endless and intimate tasks involved in feeding and caring for a baby intensifies the mother–infant relationship significantly, creating the potential for both increased satisfaction and increased stress in the maternal role. Many new mothers struggle to maintain their identity in the midst of the demands of motherhood (Jackson, 1992).

In contrast, many fathers struggle to find a way to stay involved with their new baby. Although some fathers become interested, intensely preoccupied, and absorbed with their newborn baby (Greenberg & Morris, 1974), this intensity often wanes over time. Within a few months, the level of involvement approaches a traditionally detached stance (LaRossa, 1988). Today's fathers are more involved with their children than their own fathers were with them. Nonetheless, on average, fathers typically devote "only a fraction of the mothers' [total time]" (LaRossa, 1988, p. 454) to direct and indirect child care.

LaRossa suggests that when fathers are with their children, they are often "technically present but functionally absent" (1988, p. 454). While caring for or playing with their children, fathers are often simultaneously involved in another activity, either mentally or physically. Detached caretaking reduces the potential for the intensification of the father–child relationship. Although modern fathers may want to be more involved with their children, many are not. The discrepancy causes men to feel "ambivalent and guilty about their performance as fathers" (LaRossa, 1988, p. 456). Those fathers who are intensely involved with their children may hide their involvement, fearing others might think their behaviour is "unmanly" (Greenberg & Morris, 1974, p. 527).

The relationship each parent has with the baby differs in terms of timing, intensity, and activities. It follows then that mothers and fathers might also derive satisfaction from different aspects of their parental role. Scott & Alwin (1989) found that when parents speak about their positive parenting experiences, mothers focus more on the immediate and intimate aspects of relating to and caring for their

children. Fathers tend to celebrate their children's achievements. In addition, motherhood can offer a feeling of personal fulfilment to women while fatherhood offers men a feeling of accomplishment (Knapp, 1986).

Despite the potential for rewards, in our society we have impossible expectations for both mothers and fathers. As Rando (1986a) says, "Parents are to be all–loving, all–good, all–concerned, totally selfless, and motivated only by the child and his welfare" (p. 9). Klass (1988) adds that we also expect competent parents to be able to protect their children from all harm. These expectations make it difficult for parents to admit to themselves and to others that sometimes they make mistakes, and that sometimes they feel angry, frustrated, and ambivalent about their parental role and their own children.

When parents commit themselves to caring for a new baby, they begin a new chapter in their lives. Some are ill-prepared to handle all the demands. Parenthood involves a commitment to helping children move away from "absolute dependence" to "lessening degrees of dependence, and [helping them] grope towards independence" (Winnicott, 1987b, p. 83). Each stage of a child's development stimulates new and different parent–child issues. Rando (1986a) says there is a connection between these issues and the nature of parental grief.

During the first year of life children are completely dependent upon their parents to meet their every need. Thus, two issues may arise for parents during this time: the feeling of immense and overwhelming responsibility for the baby's well–being and the struggle to find time for oneself occasionally (LaRossa, 1986; Jackson, 1992). It may take parents several months to balance their needs and their children's needs.

With the complex meanings assigned to children, the high expectations of parenthood, the development of parental identities and roles, the unique and intense histories of the mother–infant and father–infant relationships, and the dependency–related issues that occur for the parents during the first year of a child's life, it is no

wonder that the sudden death of an infant triggers an intense grief reaction.

The literature offers further suggestions about why losing an infant may trigger such intense grief. First, babies are completely dependent upon their parents, making parents feel responsible for anything that happens to them. Therefore, when a baby dies, parents feel like they have "failed totally and completely" (Klass, 1988, p. 15) at their job. Second, the death of an infant occurs at a time when physical and "psychological boundaries [between the parent and the child] overlap significantly" (Rubin, 1985, p. 347). This makes the death a physically and emotionally wrenching experience. Third, like others in our society, most parents believe in "an orderly death" (DeFrain et al., 1991, p. 86). When a baby dies, "the natural order of things [is] disrupted" (p. 86). Lastly, instead of receiving support for their grief, grieving parents may be socially isolated. Instead of understanding the depth of their love for the baby, others may say that the parents "are lucky they did not have a longer time to become attached to [the baby] or ... that they can have other children" (Rando, 1986a, p. 6).

Since these issues are present whenever an infant dies (Nichols, 1986; Stinson & Stinson, 1979), they are not enough to explain the intensity of the parental grief reaction after a baby dies of SIDS. Exploring the unique circumstances of the death itself provides a better explanation.

SIDS occurs suddenly and without warning

SIDS strikes without warning, often during the night or while the infant naps during the day. Consequently, a SIDS death hurtles parents into grief; they have no time to prepare themselves psychologically (Arnold & Gemma, 1991; Bergman et al, 1969; Cornwell, Nurcombe, & Stevens, 1977; DeFrain et al., 1991; Dyregrov & Matthiesen, 1987b; Halpern, 1972; Markusen et al., 1978; Valdes–Dapena, 1991). At least parents who know their child is ill and likely to die can brace

themselves for the emotional pain that lies ahead (Knapp, 1986; Kupst, 1986; Morrell, 1988; Stinson & Stinson, 1979). At least these parents can say their good–byes to their child. As Taylor, DeFrain, & Ernst (1986) suggest, for parents who lose a baby to SIDS, there is no time for one last hug or kiss. "The sudden absence of the baby and the futility of the parenting role after the loss makes the situation seem more overwhelming" (p. 166). Additionally, a death due to SIDS shocks parents because they believe that "babies do not just die" (Arnold & Gemma, 1991, p. 53), especially apparently healthy babies. Therefore, right from the start this death makes no sense to the parents nor to anyone else. And that is exactly why the next unique circumstance of a SIDS death occurs.

Sudden and unexpected deaths must be investigated

In most places, "all instances of sudden, unexpected death are, by law, reported to the legal authorities, usually the medical examiner or coroner, who have the responsibility of determining the cause of death" (Guist & Larsen, 1991, p. 148). This requirement involuntarily puts the parents into contact with "a system with which they have probably never previously been involved, a system that generally investigates suspicious and criminal deaths" (Arnold & Gemma, 1991, p. 53). The professionals who represent this system and the "attitudes they convey to the family, that of blame or support, can have lasting effects on the parents" (Nikolaisen & Williams, 1980, p. 595).

Initially, the police may suspect that the parents abused the baby (Arnold & Gemma, 1991; Lowman, 1979). Because of this suspicion and because some police do not know how to distinguish SIDS babies from abused babies,[5] police may treat parents like criminals (DeFrain & Ernst, 1978). Parents must also endure a medical

[5] See Guist & Larsen (1991, p. 144) for a comparison of the signs of an obviously abused baby to a baby that might have died of SIDS. The authors caution the reader to remember that only an autopsy can confirm SIDS as the cause of death.

investigation.[6] Only a pathologist can conclusively diagnose SIDS and the only diagnostic tool is an autopsy. Some parents react negatively to hearing that an autopsy is necessary for diagnosis (Smialek, 1978). Others welcome it, hoping that it will provide them with "an explanation for the death" (DeFrain et al., 1991, p. 66). Unfortunately, once parents hear the results of the autopsy, they often feel angry and cheated. Because the diagnosis of SIDS merely means that the medical experts can find no explanation for the baby's death, parents often continue to ask why their baby died. This takes us to the last and most unique features of the SIDS–loss experience.

The cause of SIDS is unknown

The "characteristic failure of the postmortem examination to provide a satisfactory explanation for the death" (Bergman et al., 1969, p. 102) significantly increases the pain and confusion of parents, siblings, and other family members (Arnold & Gemma, 1991; Cornwell et al., 1977; DeFrain & Ernst, 1978; DeFrain et al., 1991; DeFrain, Jakub, & Mendoza, 1992; Halpern, 1972; Lowman, 1979; Mandell, McAnulty, & Reece, 1980; Mandell, Dirks–Smith, & Smith, 1988; Markusen et al., 1978; May & Breme, 1982; Rubin, 1985; Smialek, 1978; Williams & Nikolaisen, 1982). Because many people "need to believe in causes for human tragedy" (Lowman, 1979, p. 765) and no specific cause can be found for this one, the parents' belief in a "rational and/or metaphysical model of the universe" (Cornwell, et al., 1977, p. 657) is severely shaken. Many people try to create their own explanations about why the baby died (Bergman et al., 1969; Cornwell et al, 1977; DeFrain et al., 1991; Williams and Nikolaisen, 1982). Most of the explanations reflect the fact that parents "almost universally

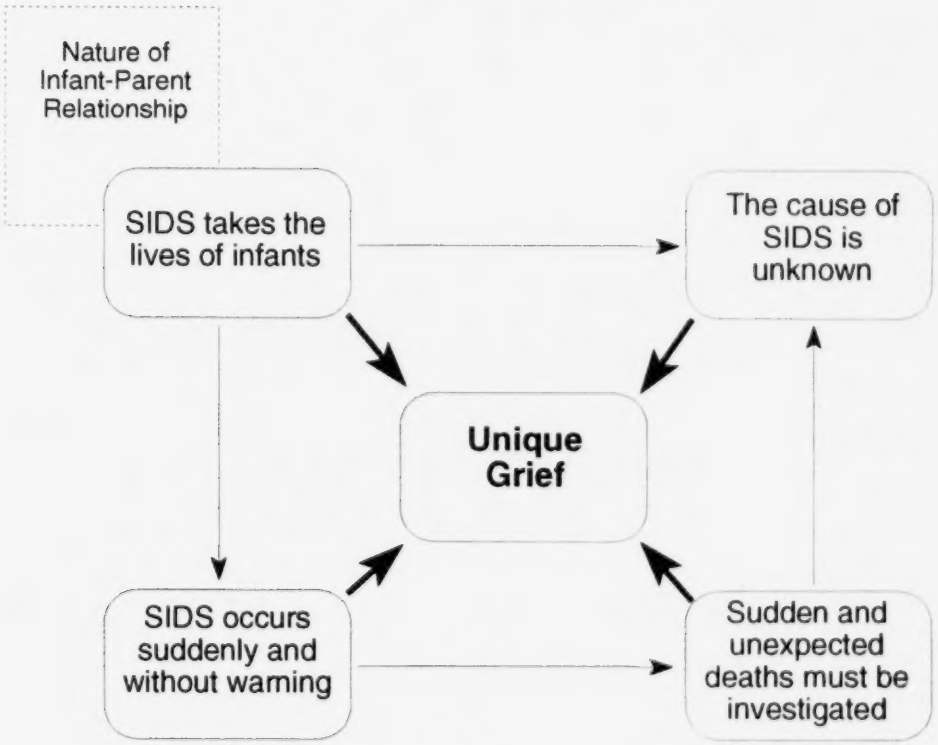
[6] Medical investigations involving autopsies are also held when children are murdered (Schmidt, 1986), when they commit suicide (Bolton, 1986), when they die accidentally (Sanders, 1986), or when they die after a serious illness (Kupst, 1986). The major difference, however, is that usually the autopsy reveals the cause or at least the circumstances of the death.

experience a feeling of ultimate responsibility [when their baby dies of SIDS]" (May & Breme, 1982, p. 61).

The unique circumstances of a SIDS death interact

When taken alone, each of these circumstances can create problems for the parents. But these circumstances do not stand alone. Instead they interact, and through their interaction, they multiply the impact. Figure Three on page 24 depicts the way these circumstances interact to produce the distinctive SIDS grief "aftermath" (Markusen et al., 1978, p. 277).

Figure Three: The Interaction of Four Unique Circumstances of a SIDS Death that Contribute to Unique Grief


Nature of Infant-Parent Relationship
SIDS takes the lives of infants
The cause of SIDS is unknown
Unique Grief
SIDS occurs suddenly and without warning
Sudden and unexpected deaths must be investigated

The SIDS Grief Aftermath

In this section I review studies that address the following subjects: early parental reactions to their baby's death, parental guilt, gender differences in grieving, grief and the parents' marriage, grief and children, and the changing nature of parental grief over time. At the end of each subject, I identify research issues and questions that should be addressed in future studies.

Early parental reactions

Emotional reactions

Within minutes of finding their baby or hearing that their baby is dead, most parents experience emotional shock (Bergman et al., 1969; Cornwell et al., 1977; DeFrain et al., 1991; Lowman, 1979; Nikolaisen & Williams, 1980). When the numbness begins to fade, parents begin to feel many emotions, most commonly: "agonizing sadness" (Cornwell et al., 1977, p. 656); sadness and depression (Bergman et al., 1969; DeFrain et al., 1991; Dyregrov & Matthiesen, 1987b; Price, Carter, Shelton, & Bendell, 1985); anxiety (DeFrain et al., 1991; Dyregrov & Matthiesen, 1987b; Rubin, 1981); and anger, general irritability, and hostility (Bergman et al., 1969; Cornwell et al., 1977; DeFrain et al., 1991). Many parents also begin to experience fear (Price et al., 1985). While some are generally afraid to be left alone in their homes, others specifically fear for the safety of their children (Bergman et al., 1969; Cornwell et al., 1977). As their emotions fluctuate from moment to moment (Bergman et al., 1969), parents soon start to feel like they are losing control of themselves.

Cognitive reactions

Besides having trouble controlling their emotions, parents are also troubled by their thoughts. Troublesome thoughts in the early stages of their grief directly relate to the unique circumstances of death

due to SIDS. Those who find their baby dead are often troubled by "intrusive thoughts of the discovery in the form of flashbacks" (Dyregrov & Matthiesen, 1987b, p. 109). No matter who finds the baby, it is not unusual for both parents to carefully review every aspect of their child care to see if they did anything or missed anything that might have caused the baby's death (Cornwell et al., 1977; DeFrain et al., 1991). Parents are often overwhelmed by thoughts of self–reproach and guilt (Bergman et al., 1969; Cornwell et al., 1977; DeFrain & Ernst, 1978; DeFrain et al., 1991; Rubin, 1985).

Within a few weeks of the baby's death, parents may also be troubled by difficulties with concentration during the day (Bergman et al., 1969; Price et al., 1985) and with disturbing dreams about the baby at night (Bergman et al., 1969; Cornwell et al., 1977). At first, some just cannot accept that their baby is dead, but when the reality of the baby's absence hits them, grief overwhelms them (Bergman et al., 1969; DeFrain et al., 1991; Lowman, 1979). Fearing that they cannot control their crazy thoughts, some parents worry that they might be "going insane" (Bergman et al., 1969, p. 102). SIDS is beginning to take its "psychiatric toll" (Bergman et al., 1969, p. 99).

Physical reactions

In addition to feeling like they might be going crazy, parents may also feel physically ill. They may experience: sleep problems, stomachaches, headaches, appetite loss, and fatigue (Bergman et al., 1969; Cornwell et al., 1977; Dyregrov & Matthiesen, 1987b; DeFrain et al., 1991; Lowman, 1979; Price et al., 1985). Some also suffer from what they call "heartaches" (Bergman et al., 1969, p. 102). Breastfeeding mothers often experience intense pain as "their breasts fill with milk" (Arnold & Gemma, 1991, p. 50) for a baby that is no longer there.

Spiritual reactions

Life may also lose all meaning for some parents; everything seems useless and pointless (Bergman et al., 1969; Cornwell et al., 1977) and nothing makes sense. Some parents lose their faith in God

entirely; others lose their faith temporarily; still others rely heavily on their faith to get them through this crisis (DeFrain et al., 1991). Some parents question whether life is worth living at all. Thoughts of suicide trouble some parents, more often mothers than fathers (Cornwell et al., 1977; DeFrain et al., 1991).

Behavioural reactions

Grief also affects parental behaviour. Many studies describe the parents' general restlessness (Bergman et al., 1969; Cornwell et al., 1977; DeFrain et al., 1991; Dyregrov & Matthiesen, 1987b; Price et al., 1985). Some parents keep searching for their baby and doing things as if the baby still needed their attention (Bergman et al., 1969; Cornwell et al., 1977; DeFrain et al., 1991). To avoid the constant reminders of their baby and their horrible discovery, many parents just want to move away (Bergman et al., 1969; DeFrain & Ernst, 1978; Lowman, 1979).[7] Over half the parents who participated in the Price et al. study (1985) moved shortly after the baby's death, half within the first month.

Some parents weep almost continuously; they cannot function effectively at all. Others perform all their duties without any sign of their inner pain (Cornwell et al., 1977). Many feel no interest in social activities; some begin to experience difficulties at work. Women often feel uncomfortable in the presence of pregnant women (Price et al., 1985). To block their pain, some parents increase their smoking, drinking, and "self–injurious behaviour" (Lowman, 1979, p. 674). Some actually attempt suicide (Cornwell et al., 1977; DeFrain et al., 1991).

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[7] Because so many families move after the death of their baby to SIDS, we may not have an accurate picture of the severity of the parents' devastation. Those who move so suddenly may be the most severely affected and most in need of follow-up help. They are also least likely to participate in survey research that depends upon contact by mail. For example, Price et al. (1985) had over one-third of their questionnaires returned because the families had moved and left no forwarding address. Other authors had similar problems (Cornwell et al., 1977; DeFrain & Ernst, 1978; Lowman, 1979).

Research issues and questions

After reviewing all these findings, all we have is a list of the many ways in which grief affects parents emotionally, cognitively, physically, spiritually, and behaviourally. A list of reactions does not tell us how these parents cope with their grief. We still do not know how parents make the transition from being overwhelmed by their grief to managing their grief to living a "normal life" again (Cornwell et al., 1977, p. 658). Lastly, we do not know why some parents seem to grow stronger as a result of this experience while others never seem to recover from their baby's death (DeFrain et al., 1991).

Parental guilt

Grief and the pervasiveness of parental guilt

Bergman et al. (1969) were among the first to notice the "pervasiveness of the parental guilt reaction" (p. 99) among SIDS parents. Their observation has been repeatedly confirmed by other studies (Cornwell et al., 1977; Dyregrov & Matthiesen, 1987b; DeFrain & Ernst, 1978; DeFrain et al., 1991; Halpern, 1972; Lowman, 1979; Mandell & Wolfe, 1975; Mandell et al., 1980; Markusen et al., 1978; Price et al., 1985; Rubin, 1985; Williams & Nikolaisen, 1982).

Although many grieving parents struggle with guilt (Miles & Demi, 1986; Johnson–Soderberg, 1983; Peppers & Knapp, 1980; Rando, 1985), parents whose children die suddenly seem to experience it more often. Johnson–Soderberg found that parents whose child died suddenly (some of SIDS) made close to three times as many guilt statements during interviews as parents who had known that their child was dying. When compared to mothers who had lost infants to a variety of other causes, guilt "penetrated the very core of the existence" of mothers who had lost babies to SIDS (Peppers & Knapp, 1980, p. 37). Guilt is "an overpowering and dominant feature of the entire grieving process" (p. 37) for parents who lose a baby to SIDS. It becomes almost "inescapable" (DeFrain et al., 1991, p. 77).

Sources of guilt

Many parents know it makes no sense for them to feel responsible for their baby's death, especially once they start to understand more about SIDS. Nevertheless, many parents continue to feel guilty. Feeling guilty is "a source of dissonance" because it is "at variance with their intellectual knowledge of how they ought to be responding, and at odds with their knowledge of the syndrome itself" (Rubin, 1985, p. 350). Why then do parents continue to feel guilty, sometimes for the rest of their lives?

Bugen's (1983) two–dimensional model helps to explain variations in the intensity and duration of grief. Indirectly, it also sheds some light on parental guilt after a baby dies of SIDS. Bugen's first dimension concerns the centrality of the lost relationship. The more valued the lost person, the more intense the grief. The second dimension is belief in the preventability of the death. Bugen predicts that the most intense grief reactions will occur when people lose a special loved one and when they believe that somehow they "contributed to the death, either directly or indirectly" (p. 360). The determining fact is the "perception of preventability" (p. 357), not the reality of the situation. This describes the situation for many parents who lose a baby to SIDS.

Other authors support Bugen's preventability dimension. Parents hold themselves responsible for the death of their baby, no matter what the realities of the circumstances were (Cornwell et al., 1977; DeFrain & Ernst, 1978; DeFrain et al., 1991; Lowman, 1979; Mandell & Wolfe, 1975; May & Breme, 1982; Markusen et al., 1978; Miles & Demi, 1986; Rubin, 1985). Additionally, Mandell et al. (1980) found that some grieving fathers feel guilty about being minimally involved with the baby while he or she was alive. When the baby dies, these fathers realize that they did not make the baby a central part of their lives; they also realize that they will never get another chance.

The unique circumstances that surround a SIDS death also set the stage for parental guilt. Without an adequate explanation to prove that they are not responsible, parents examine and reexamine every

aspect of their care, looking for the one thing that might have caused their baby's death (Cornwell et al., 1977). Some parents experience "secret guilt 'movies'" (Johnson–Soderberg, 1983, p. 60) - a continual replaying of the discovery scene that makes them feel like they are going crazy. This is complicated by the fact that police may treat parents like homicide suspects. Since no one can prove who or what caused the death, parents often decide they must be guilty of inadvertently causing their baby's death (Markusen et al., 1978).

Bergman et al. (1969), Lowman (1979), Markusen et al. (1978), and Bugen (1983) believe professionals can prevent or reduce parents' feelings of guilt by carefully explaining to parents everything there is to know about SIDS, Even after parents hear a detailed explanation, they may still say, "SIDS just isn't enough of an answer" (DeFrain et al., 1992, p. 169). What more do they need?

Parents' attempts to explain their baby's death

Perhaps to reduce their guilt, parents seem to need a "concrete answer" (DeFrain et al., 1992, p. 169) to their question, Why did our baby die? They need an explanation that "makes sense" (Cornwell et al., 1977, p. 658) to them. The baby's death causes the parents to have "an insecure feeling that [other] things can be taken away" (Cornwell et al., 1977, p. 658) too. So, without a definitive or acceptable explanation from anyone else, parents begin to construct their own.

More parents believe the real cause of their baby's death was suffocation than any other explanation (Cornwell et al., 1977; DeFrain et al., 1991; Williams & Nikolaisen, 1982; Bergman et al., 1969). Other concrete parental explanations include: choking, unsuspected illness, sibling caused death, haemorrhaging, brain virus, air pollution, atomic testing, freezing, reaction to shots, baby cried self "to death" (Bergman et al., 1969, p. 102); neglect, injury, birth defects, maternal error, and allergies (Williams & Nikolaisen, 1982); the baby forgot to breathe, had a respiratory illness like a cold or pneumonia, or was born

prematurely (DeFrain et al., 1991).[8] Most of these explanations hint at parental self–blame or the need to blame another instead. Most parents look beyond just physical explanations.

Parents also look for metaphysical or religious explanations (Cornwell et al., 1977). Some decide that God took their baby (DeFrain et al., 1991). While this thought makes some parents question God's nature and wisdom (Cornwell et al., 1977), others believe in a punishing God (Williams & Nikolaisen, 1982) or a God that would take their baby as a test of faith (Cornwell et al., 1977). Some parents choose to believe their baby was fated to die or died because of bad luck (Williams & Nikolaisen, 1982).

Research issues and questions

These studies suggest that parents create many possible explanations for their baby's death; most explanations reflect the acceptance of parental responsibility. How then do they decide which one to accept? What criteria do they use to make this decision? Is this decision made just once or twice or do parents keep changing their minds about why their baby died? And what makes them change their minds?

Cornwell et al. (1977) provide us with some clues to these questions. Fortunately, besides administering questionnaires, these authors also interviewed the parents three or four times during the first year after the baby's death. Rather than subjecting their interviews to rigorous analysis, however, Cornwell et al. merely summarize the issues.

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[8] Siblings also try to explain the death. Smialek (1978) overheard older siblings saying that their baby brother or sister had died because: "He died because he was bad - he wouldn't stop crying. Mommy dropped him on his head. I hit him. God wanted him" (p. 164). According to DeFrain et al. (1992), grandparents also need to understand why the baby died. Grandparents construct explanations similar to those given by parents, with one exception. Some grandparents, particularly those who are ill or elderly, question why a healthy baby would die while they live on (Marquez, 1991).

The issues they identify are very telling. This study hints at the existence of an explanation–seeking and guilt–reducing process that parents work through over time.

> Parents often **initially** [emphasis added] felt guilty and thought that the death was their fault ... (p. 657).

> Attempts were made to fit the event into a rational and/or metaphysical model of the universe. The parents **struggled with attempts to make sense** [emphasis added] of a sudden inexplicable disastrous event. In this country, parents expect their babies to live. When this confident expectation is shattered, a massive revision may take place in their understanding of what the world is about. ... (p. 658).

> Parents **attempted to maintain** [emphasis added] their belief in a benign God, and several **convinced themselves** [emphasis added] that the child would have been physically, intellectually or morally defective, had it lived (p. 658).

This study suggests that parents work hard to construct their explanation; they construct several possible explanations over the course of a year; they struggle to decide which one to settle on; they have to resolve some inner conflict in the process; and that parents feel stressed until they can resolve their conflict. The Cornwell et al. study provides a fresh perspective on parental guilt. Although this study was reported in 1977, no one has investigated this subject further. This important topic warrants further investigation.

Grief and gender differences

Most of the research on this topic looks at differences between the experiences of mothers and fathers. On average, paternal grief seems less intense and shorter in duration than maternal grief (Cornwell et al., 1977; Dyregrov & Matthiesen, 1987a). Fathers in the Cornwell et al. study took a little less than four months to feel like they had returned to "normal functioning" (p. 658) while it took the mothers just over ten months. Fathers also accept SIDS as the cause of their baby's death sooner than mothers (Williams & Nikolaisen, 1982).

In the DeFrain et al. (1991) study, 93% of the participants said that "their way of coping was different from that of their spouse" (p. 104). While personality differences may account for some of this variation, several authors suggest that sex roles may also affect how parents deal with their grief (Cook, 1988; DeFrain et al., 1991; Dyregrov & Matthiesen, 1987a; Fish, 1986; Mandell et al., 1980; Rando, 1985).

Mandell et al. (1980) observed that grieving mothers appear depressed and withdrawn. In contrast, other authors find that instead of withdrawing, many women cry openly and want to talk about their experience (DeFrain et al., 1991; Nikolaisen & Williams, 1980).

Women take advantage of the opportunity to share their grief with others. In contrast, most men feel reluctant to talk about their grief, partly because, as one man said, talking "won't bring the baby back" (Mandell et al., 1980, p. 223). Instead of talking, men are more likely to: concern themselves with their wives' well–being, (Cornwell et al., 1977), increase their work involvement (Nikolaisen & Williams, 1980; Mandell et al., 1980), assume the role of manager, suggest having another baby, and "intellectualize" their pain (Mandell et al., 1980, p. 222). Men are also less likely than women to participate in support programs (Mandell et al., 1980).

Research issues and questions

Sometimes what we learn about grief reactions in one gender stimulates questions about reactions in the other gender. Rubin (1985) found "the permanent presence of the child in the maternal experience" (p. 351). Do fathers also maintain an emotional connection to a "phantom child" (p. 351)? If not, why not and how and when do they let go of the baby? Price et al. (1985) found that the younger the baby at the time of death, the more difficult the mother's adjustment. Does the baby's age affect the father's adjustment in the same way? If fathers really do accept SIDS as the diagnosis more readily than mothers (Williams & Nikolaisen, 1982), why and how does this happen? What

prevents mothers from accepting this explanation any sooner? And, if fathers seem to return to normal functioning sooner than mothers (Cornwell et al., 1977), what contributes to this? Lastly, why might women want to talk about their grief and men resist talking? Is this true for all men and all women? Despite much research in this area, obviously many questions remain unanswered.

Grief and the parents' marriage

Incidence of divorce

"The death of a child may be viewed as a crisis point or pivotal point that either results in increased supportiveness within the marital relationship or in increased estrangement from one's spouse" (Price et al., 1985, p. 26). The baby's death changed ninety percent of the marriages in the DeFrain et al. (1991) study. Many couples experience a severe crisis in their relationship. Some separate or divorce within the first year or two after their baby's death (Cornwell et al., 1977; DeFrain et al., 1991; Mandell et al, 1980). Estimates about the divorce rate for these parents vary considerably. DeFrain et al. (1991) suggest the divorce rate is really no higher for these parents than for the general population. These authors suggest that those parents who do divorce seldom blame the baby's death; they list other problems instead. Part of the problem is that no one has completed a longitudinal study of the divorce rates for parents who lose a baby to SIDS.

Weakened relationships

While some couples separate or divorce, others stay together although their marriage is weakened, more emotionally distant, or in crisis within months of the baby's death. The percentage of weakened but intact marriages varies across the studies: 35% of the men and 22% of the women in DeFrain et al (1991); 33% of the couples in Cornwell et al. (1977); 30% of the women in Price et al. (1985); and 21% of the couples in Mandell et al. (1980). The extent of marital problems varies from increased fighting or distance to "a defined need for marital therapy" (Cornwell et al., 1977, p. 657).

Some marriages are in trouble even before their baby's death. "Anything that was wrong [with the marriage] before [may be] augmented one hundredfold" (DeFrain et al., 1991, p. 198). Young parents with few problem solving skills may have had no previous experience with death and grief (Markusen et al., 1978). Consequently, they may not know how to talk about their grief and how to solve problems together. If a couple marries primarily because of a pregnancy and then the baby dies, then they may have little commitment to staying together (Mandell et al., 1980). But the death of a baby can strain even a solid and mature marriage.

Strained marriages

"Grief can be simultaneously both a shared and an intensely private experience" (Ranney, 1991, p. 59), partly because parents each handle their grief in their own unique way. Many researchers assume that gender is at the root of this uniqueness (Cornwell et al., 1977; DeFrain et al., 1991; Mandell et al., 1980; Ranney, 1991; Williams & Nikolaisen, 1982). To further complicate matters, some parents cannot understand or tolerate differences in the way people grieve. Instead they try to change their spouse's behaviour. This leads to increased fighting and more misunderstandings (DeFrain et al., 1991; Nikolaisen & Williams, 1980; Rando, 1985). For instance, Miles (1975, cited in Nikolaisen & Williams, 1980) says that some men consider their wives to be "uncontrolled and weak" while wives think their husbands are "uncaring" (p. 594). These kinds of comments may significantly increase marital tension.

Grief also affects the way couples function as partners. Writing generally about parental grief, Rando (1985) says that both parents often simultaneously lose their major source of support - each other. If parents cannot get past this problem, they may feel abandoned, leading to less than positive evaluations of their relationship. Thirty–eight percent of the parents in the Cornwell et al. (1977) study said that their baby's death had negatively affected their ability to function as a marriage partner. Grieving parents also have little energy because it is "spent trying to cope with the death" (DeFrain et al., 1991, p. 198). Soon husbands and wives have nothing "to give anymore, and when

you're not giving in a marriage at all times, that marriage can quickly fall apart" (DeFrain et al., 1991, p. 107).

Grieving parents may also experience communication problems (Rando, 1985). Although May & Breme (1982) suggest that couples should discuss their grief, many couples find it difficult to talk about their pain (DeFrain et al., 1991; Mandell et al., 1980) or when one wants to talk, the other does not (Dyregrov & Matthiesen, 1987a). Couples may not even share their tears, sometimes because when one partner sees the other cry it causes both to cry. Cornwell et al. (1977) call this "resonating grief" (p. 657). Because of resonating grief, some partners start hiding their tears. It is difficult to tell whether this has a positive or negative effect on marriages. Dyregrov & Matthiesen (1987a) also found something similar. They called it "reciprocal emotional influence" (p. 12). These authors suggest that when parents trigger grief in each other, it may be a sign that they need professional help.

Grieving may also affect marital intimacy. Fifty–two percent of the respondents in the DeFrain et al. (1991) study reported that their sexual relationship had changed. Some spouses feel they are not functioning well as sexual partners (Cornwell et al., 1977). Shortly after the baby's death, a woman's interest in sex may become almost nonexistent while her husband's may increase significantly (DeFrain et al., 1991). This can become another major source of conflict.

At the same time, the couple may be trying to decide whether to have another baby. This can be a difficult decision at the best of times. If both partners are feeling raw and overwhelmed by their grief, then it can severely strain any marriage (DeFrain et al., 1991; Mandell et al., 1980).

Possible difficulties with conception and then the subsequent pregnancy (Mandell & Wolfe, 1975), the birth of a new baby, and then trying to care for and love this new baby while fearing its death (Bergman et al., 1969; Cornwell et al., 1977; DeFrain et al., 1991) can strain any marriage. And what about the mother's continued connection

to her "phantom child" (Rubin, 1985, p. 351)? As yet, we do not know if fathers share in the memories and "bittersweet current relationship" (p. 350).

Strengthened marriages

While it is true that many marriages are strained to the limit by grieving, many parents have the opposite experience: this crisis strengthens their relationship. Many couples feel more closely tied to one another (43% in Cornwell et al. (1977); 51% in DeFrain et al. (1991); and 60% of the women in Price et al. (1985). Although studies have identified the strains that might cause marriages to "fragment" (Mandell et al., 1980, p. 223) after the death of a child, there is little about how or why couples in the same situation might become closer and stronger.

After a thorough review of the literature, I discovered only one reference specific to SIDS that presents some ideas about how families survive. Based on the comments and answers on questionnaires from individual parents (not couples), DeFrain et al. (1991) suggest that the following factors might make a positive difference: belief in God; "commitment, togetherness, and the ability to take turns being strong for each other" (p. 204); and, lastly, the sheer will and desire to survive. These authors also suggest that effective communication within the family and with others outside the family makes a significant difference. Using individual and couple data from bereaved parents (SIDS parents included), Dyregrov & Matthiesen (1987a) found a positive correlation between a couple's ability to talk about "what happened" (p. 7) and a feeling of closeness in the marriage.

To gather more information, I expanded my search to include studies about the marital issues of grieving parents in general. Again, most researchers focus on the potential for increased problems and pain in the marriage (See Feeley & Gottlieb, 1988; Lehman, Lang, Wortman, & Sorenson, 1989; Valeriote & Fine, 1987) rather than on the potential for increased strength and closeness.

Research issues and questions

There is an obvious and major gap in the research. To date, researchers have focused all their attention on identifying and listing the problems couples face when they lose a baby to SIDS. No one has studied couples who have successfully dealt with their grief while maintaining their relationship; no one has asked these couples to share their secret strategies. These couples must be confronted by the same grief–related problems as other bereaved parents. How do successful couples surmount these problems? How do they prevent grief from hurting their relationship? Why do some relationships become stronger and others become weaker? Couples whose marriages become stronger have much to teach researchers. It is time someone asked for these couples for direct help in understanding this important issue.

Grief and siblings[9]

The death of an only child

Before discussing how older siblings might be affected by the death of the baby, a few words about parents who lose their first and only baby to SIDS. Although SIDS takes fewer firstborn babies (Hillman, 1991), it does take some. Thirty–two percent of the mothers in the Price et al. (1985) study and twenty–nine percent of the couples in the Lowman (1979) study lost their firstborn babies. Parents who lose their only child "experience a complete cessation of parental responsibilities, as well as gratifications, [and they] are forced to contend with a total lack of experiences reinforcing their former parental identities" (Rando, 1986a, p. 32). In contrast, parents who have other children still feel like parents, still have others treating them like parents, and still have someone needing them to be acting like parents.

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[9] Because the focus of this study is parental grief, in this section I only highlight findings that relate to how the children's reactions might affect the parents' grief. The subject of sibling grief is large enough to warrant a separate study.

Research issues and questions

This difference is likely to affect the nature and intensity of parental grief, but most researchers ignore this. They seldom specify whether parents in their studies have lost their only child or whether they have other children (see Bergman et al., 1969; Cornwell et al., 1977; DeFrain & Ernst, 1978; DeFrain et al., 1991; Dyregrov & Matthiesen, 1987b; Mandell et al., 1980; Nikolaisen & Williams, 1980; Rubin, 1985; Williams & Nikolaisen, 1982). If researchers want to understand all the issues that contribute to the intensity and duration of the parental grief experience, the importance of birth order should not be ignored.

Older siblings

Since the "risk [of SIDS] increases steadily with increasing parity" (Hillman, 1991, p. 17), most parents who lose a baby to SIDS have at least one older child. For example, sixty–eight percent of the women in the Price et al. study (1985) had at least one older child. And some of these older children witness the discovery of the dead baby (Mandell et al., 1988).

Most children cannot comprehend the meaning of this event: they wonder about other people's behaviour; they wonder if perhaps something they said or did or thought made the baby die (Mandell et al., 1983; Mandell et al., 1988). They may remember not wanting the baby or feeling angry sometimes (Halpern, 1972). This leads to guilt feelings and, sometimes, a feeling of responsibility for the death. Additionally, Halpern found that when parents handle this crisis poorly, the children suffer. Some children think the parents are upset because of something they have done wrong (Burns, House, & Ankenbauer, 1986).

Price et al. (1985) believe that children will be upset, no matter how parents handle their own grief because

> with the emotional demands that the death of an infant places upon the parents, the surviving siblings must often endure more than one

> loss. That is, the child experiences both the death of a sibling and the feelings of loss associated with the decreased emotional availability of the parents in their attempt to cope with their own grief (p. 26).

Several studies do show that parental behaviour changes after the death of a baby. In addition to, or perhaps as a consequence of, feeling overwhelmed with grief themselves, some mothers withdraw from or reject their other children (Cornwell et al., 1977; DeFrain et al., 1991; Halpern, 1972; Mandell et al., 1983; Price et al., 1985). Halpern (1972) suggests that the very circumstances of a SIDS death contribute to the problem of parental behaviour: the inexplicable and sudden death of the baby devastates and overwhelms the parents. They may be short-tempered and find it difficult to talk with or feel empathy for their other children. Some distressed parents overtly blame their older child for causing the baby's death. This can devastate the child.

Instead of rejecting their children, most parents do the opposite: they try to get closer to their surviving children (Mandell et al., 1983). Seventy percent of the mothers in the Price et al. (1985) study reported that they felt closer to their surviving children after the baby's death. Many parents go beyond normal emotional closeness. Numerous studies say that parents grieving the loss of a baby to SIDS very often become very overprotective parents (Bergman et al., 1969; Cornwell et al., 1977; DeFrain & Ernst, 1978; DeFrain et al., 1991; Mandell et al., 1983; Rubin, 1981).

How does overprotectiveness translate into behaviour? Overprotective parents commonly check their children continually, particularly while the children sleep (Cornwell et al., 1977; DeFrain et al., 1991). Parents may also overindulge their children and appreciate them more. They may become more permissive or worried about their children's health. Some parents become inconsistent with rules and discipline (DeFrain et al., 1991; Mandell et al., 1983). While 47% of the parents in the Cornwell et al. (1977) study felt that their parenting improved after the baby's death, 33% felt their parenting skills had suffered.

Most older siblings experience significant difficulties after the death of their brother or sister. Studies vary as to the number of parents who say their children seemed disturbed by the baby's death: 97% in Mandell et al. (1983) to 78% in DeFrain & Ernst (1978). Fifty–three percent of the mothers in the Price et al. (1985) thought their children were "noticeably disturbed" (p. 26) in the first weeks after the baby's death. The authors do not explain the nature or severity of these disturbances.

Most studies examine children's immediate reactions and then some follow them for the first year. According to the parents in the Cornwell et al. (1977) study, children's reactions varied with their age. After the death of the baby, toddlers rejected their mothers, had temper tantrums, and kept looking for the baby. Older children repeatedly asked questions about the baby's death and what had happened to the baby's body. They also worried about their own impending death. Children under twelve had trouble sleeping; they often felt afraid.

In the Mandell et al. (1983) study, 83% of the children aged two to two and a half had sleep problems: these children resisted going to bed, then they had trouble falling asleep and staying asleep. In their nightmares, "monsters" pursued them, the same monsters that had "killed" (p. 654) their baby brother or sister. Fifty percent of the 30 to 48 month old children in one study had significant changes in the way they interacted with other children. While some withdrew, others became aggressive to the point that schools and day care centres expressed concern (Mandell et al., 1983; DeFrain & Ernst, 1978). Other problems included regression in toilet training (DeFrain & Ernst, 1978; Mandell et al., 1983), appetite disturbances (Mandell et al., 1983), bed wetting, crying a lot, and blackouts (DeFrain & Ernst, 1978).

Children's reactions varied over time (Davies & Segal, 1991). At first, the parents' reactions frighten and upset the children more than anything else. Gradually, as the children begin to comprehend that the baby really is gone, they react more openly. In the Price et al. study (1985), after six months "only 10%" of the children remained

"significantly disturb[ed]" (p. 26). Just over half the children seem to have difficulties beyond the one year mark (Burns et al., 1986). Some children still seem angry at the end of the first year, particularly with their mother (Cornwell et al., 1977). The three children described in the Halpern (1972) article were all seen in a child guidance clinic within twelve to eighteen months of the SIDS death. Their reactions were so severe that they required the intervention of a child psychiatrist. And then there is the lasting legacy of losing a sibling to SIDS. Mandell et al. (1988) found that when some siblings become parents themselves, they become afraid they will lose their own baby to SIDS.

Research issues and questions

Since the major focus of this review of the research is about parental grief, my questions relate mostly to the parents in relation to their older children. What causes the parents to overprotect their older children? Is there a connection between the lack of a definite explanation for the baby's death and the parents' need to overprotect their surviving children? How long do parents continue to feel overprotective? How do they stop? Can they ever go back to being the kind of parents they were before the baby died? Do both mothers and fathers overprotect? How does this kind of parenting affect the parents' marriage and the parent–child relationship in both the short–term and the long–term? We have no answers to these questions to date.

I have further questions. Why might some parents feel better and others feel worse about themselves as parents? Lastly, what role does the child play in how the parents feel? Does the behaviour of the child influence the parents' grief in any way? Clearly, this whole subject requires further exploration.

Subsequent pregnancies and children

Most parents who lose a baby to SIDS eventually want to have another baby (Mandell & Wolfe, 1975; Mandell et al., 1982; Price et al., 1985). While some want to get pregnant within weeks of the baby's death, others put off the decision until they feel less stressed and until

they feel able to accept another baby as a separate person (Cornwell et al., 1977; DeFrain et al., 1991). Some parents decide not to have any more children (Cornwell et al., 1977; DeFrain et al., 1991; Mandell & Wolfe, 1975), often because they are "uncertain that they would be able to cope with further pain if they lost it" (Cornwell et al., 1977, p. 657). There is an important time element here though. DeFrain et al. (1991) found that, for some parents, this fear decreases over time causing some parents to change their minds.

When researchers look at this decision, they usually treat it as a women's issue (Mandell & Wolfe, 1975; Price et al., 1985). When the thoughts of both parents are studied, however, it reveals the source of possible marital conflict. While almost all the fathers in the Mandell et al. (1980) study wanted to have another baby very soon, their wives did not share this desire, mostly because they feared losing another baby. Because of their differences, "the issue of a subsequent pregnancy [became] a source of conflict between the parents" (Mandell et al., 1980, p. 222). Although many couples do eventually have another baby, little is known about how they deal with this conflict. Instead, researchers just report on the outcome of the parents' decision: the number of babies born after a SIDS death.

When parents decide to have another baby it is either because they want a sibling for their other children or because they "need to fill the 'hole' left by the child who died" (DeFrain et al., 1991, p. 186). Once couples make the decision, some deliberately plan "for conception at a certain time so the baby could be born when there was a statistically lower chance of [a SIDS] death" (Cornwell et al., 1977, p. 657).

Despite all their planning and their desire to have another baby, some parents never conceive or deliver another baby. Others take far longer to conceive than they anticipated. In the Mandell & Wolfe (1975) study, 60% of the parents who wanted to conceive had "complications" (p. 77). Of those who had complications, 31% miscarried. Thirty–four percent did not conceive within the first year and, on average, it took parents 2.2 years to conceive again (the range

was 1.2 years to 7 years). None of these women had any previous difficulties with conception or fertility.

Mandell & Wolfe (1975) suggest that the women's intense grief reaction may affect their menstrual cycle, thereby making it more difficult to either conceive or carry a baby to term. While this medical explanation makes good sense, it ignores the possibility that stress within the marriage might also contribute to the problem. The stress of first losing a baby to SIDS and then having difficulties conceiving or delivering the next baby is enough to strain any marriage.

If and when parents finally do have another baby, they begin to "suffer" from an intense fear that this baby will die from the minute they bring the baby home from the hospital (Cornwell et al., 1977, p. 657). At first, the new baby continually reminds the parents of the baby they lost: some call the new baby the wrong name occasionally. Parents check and recheck this baby to make sure it is breathing, especially during sleep. Some parents use a mechanical monitor to watch over their baby as well, although the use of these devices has decreased since the 1980's (DeFrain et al., 1991). Parents in the Cornwell et al. (1977) study took all kinds of specific precautions, like taking a first–aide course, putting screens on the windows to keep the flies out, and giving up smoking. No matter what parents do to protect their baby from "the unknown force" (Cornwell et al., 1977, p. 657) that took the other baby, they feel stressed and afraid.

Research issues and questions

Stephenson (1986) writes about the "unhealthy coping mechanism" (p. 335) of having a "replacement child" (p. 336) to cope with parental grief. He goes on to suggest that parents take "sufficient time" (p. 336) before having another child. He does not define how long they should wait. This illustrates a problem with this particular subject. We do not know what effect having another baby has on parental grief and whether the timing of the next pregnancy makes any difference. We also know little about how parents make this decision or what the next pregnancy might be like for these parents. There is even less information about parents who decide not to have another

child. Does this decision affect their marriage and their ability to heal from their loss? This whole topic needs further in-depth study if we want to understand all the issues related to the SIDS grief aftermath.

The changing nature of parental grief over time

Symptoms and consequences

Lowman (1979) suggests that parental "dissipates in time" (p. 673). For at least the first few months parents feel numb (Cornwell et al., 1977). Then the acute and intense pain of grief sets in, bringing with it all the many thoughts and feelings described earlier in this review. Within six months though, many mothers report a reduction in the total number of symptoms of grief that they experience (Lowman, 1979; Price et al., 1985;). Within less than a year after their baby's death, most parents in the Cornwell et al. (1977) study said they could at least function again. Price et al. (1985) found that although the number of symptoms decreases within the first six months, something else happens. In almost half of the women in this study, "primary symptoms (i.e. significant feelings of fear, sadness, and depression" (p. 28) persisted for well over six to thirty months longer. Dyregrov & Matthiesen (1987a) had similar findings. These studies suggest that grief may go underground, that is, become a much more private experience, after about six months.

Estimates of the number of parents who experience significant difficulties vary with the study, the methods used, and the nature of the sample. One–quarter of the mothers in the Price et al. (1985) study had an "unsatisfactory adjustment" (p. 28) to their baby's death at the end of six months. The authors do not define what they mean by this term. They also fail to describe how this adjustment problem manifested itself in the women's lives. Lowman (1979) also looked at adjustment in women over the first six months. He assumed that a steady decline in the number of symptoms was equivalent to a steady decline in "significant mourning and disruption in [the women's] lives" (p. 673). Thirty–five percent of the women in his study did not report a lessening

of symptoms; he labelled these women "maladaptive" (p. 673). Three women in the Cornwell et al. (1977) study sought psychiatric help for serious problems within the first year. No one looked at the nature of the fathers' experiences within the first six months. The longer term perspective on the mental health consequences of losing a baby to SIDS is also missing: to date studies only focus on the first six years after the baby's death.

Rubin (1981) compared the number of symptoms of grief in women whose baby had died between two and six years previously with women who had not lost their baby; the two groups were indistinguishable. Does this mean that parents are finished grieving within about six years and that most return to "normal life" (Cornwell et al., 1977, p. 658) again? Perhaps not. Although parents in the DeFrain et al.'s study (1991) may not have measurable symptoms of grief anymore, the poignancy of their storied shows that parental grief may actually last a lifetime. Some parents wrote about deaths that occurred over thirty–five years ago. Their pain seems fresh and new, their wound still raw. What then do these parents do with this pain when no one encourages them to share it? Where does it go?

Rubin (1985) did find one aspect of grief that did not decrease over time: guilt over the baby's death. He suggests that "persistent feelings of guilt" (p. 350) are characteristic of parents (particularly mothers) who have lost a baby to SIDS. He further suggests that there is no relationship between the presence of guilt and the inability to resolve the loss successfully. This begs the question then: how can a parent feel responsible for the baby's death and resolve the loss at the same time? This is a subject for further inquiry.

Continued connection to the baby

For the first month or two after the baby's death, parents' "minds were attuned to perceptions of the baby" (Cornwell et al., 1977, p. 657). Some mothers respond to what they think is their baby's cry: they prepare bottles and frequently go into the nursery. While some just worry about their baby being cold or wet in the grave, others actively try to dig up their baby. Women in particular are often frustrated

because they want "to go about their mothering tasks" (p. 657): their bodies and arms ache to hold the baby (Arnold and Gemma, 1991). But there is no baby to feed, no baby to hold and touch. Despite the passage of six to thirty months, thirty percent of the mothers in the Price et al. (1985) study reported "having difficulty with thoughts that [their] baby is still alive" (p. 26). It seems that although physical parenting becomes impossible, the emotional connection continues. Even if they have no physical body to care for, most mothers stay bonded to their baby for the rest of their life (DeFrain et al., 1991; Rubin, 1981, 1985; Price et al., 1985). Rubin (1985) suggests that parents can resolve their grief without "withdrawing all interest from the memory of the lost child" (p. 351).

At first, this continued connection to the baby seems to cause pain for the parents. One year after the death of their own infant, over 70% of the parents in Cornwell et al. (1977) study were still "visually alert" (p. 658) for babies. Mothers "thought and dreamt of their babies and looked at mementoes" (p. 658) while fathers were less likely to do this. Rubin's (1981) study shows that during the first year of bereavement, the mothers' intense attachment to their baby "intruded a significant proportion of the time or interfered with functioning significantly" (p. 107).

What happens to this attachment after a couple of years? Mothers who lost their baby an average of four and a half years earlier "demonstrated a more subdued, continuing involvement with the dead child" (Rubin, 1981, p. 108) than those with a more recent loss. Stories from DeFrain et al. (1991) suggest that this connection continues for many parents, for mothers more so than fathers. We have very little information about fathers and whether they maintain a steady and private relationship with their baby like many mothers do. However, studies do show that many mothers and fathers remember their baby at certain times of the year.

Many, but not all, parents remember their baby and perhaps experience a surge of grief on the anniversary of the baby's death (Cornwell et al., 1977; DeFrain et al., 1991; Halpern, 1972), on the

baby's birthday, special family holidays, and missed milestone events (DeFrain et al., 1991) like beginning or ending school. We know little about how parents deal with these days and why some parents remember these days and others do not.

Research issues and questions

The importance researchers give to the passage of time varies: some make an issue of it while others scarcely mention it. It seems important to ask whether the passage of time is an important issue for the understanding of the parental grief experience. Does the proverbial saying, time will heal, have any relevance at all to parental grief?

Although DeFrain et al. (1991) conclude that many parents continue to deal with their grief for the rest of their lives, many researchers examine only the parents' first year of grief (Bergman et al., 1969; Cornwell et al., 1977; Halpern, 1972; Lowman, 1979; Mandell et al., 1980). Others look at the first three years (DeFrain & Ernst, 1978; Price et al., 1985). While some studies look at how parents manage up to six years later (Dyregrov & Matthiesen, 1987b; Mandell & Wolfe, 1975; Nikolaisen & Williams, 1980; Rubin, 1981, 1985; Williams & Nikolaisen, 1982), only DeFrain et al. (1991) studied how parents manage more than six years later. These researchers did not do this intentionally but, because they did not set a time limit for participation in their study, they received information from parents whose baby had more than six years earlier. Although the DeFrain et al. study showed that grief after the death of a child is a lifelong experience, it did not help us understand how these parents deal with their grief as the years pass.

We know something about the mothers' first six months of grief, but very little about the fathers' experience. Therefore, I have more questions. How does grief change after six years? Is there a smooth reduction in symptoms? What does the trajectory of grief look like over time? What influences this experience? Is it any different for fathers than mothers? Do fathers have difficulty at certain times of the year?

If not, why not? Do fathers continue to have a relationship with their deceased baby like many mothers do? What transforms the parent-child relationship from an intense to a subdued connection? All these unanswered questions point to the need for further study.

Conclusion

This concludes the review and critique of the research. As I have shown, there are many unanswered questions, some poorly answered questions, and the beginnings of some good research. Before launching a new study to deal with these gaps in our knowledge, however, it is important that we examine the methodologies used to produce this research in the first place. I do this in the next chapter.

Chapter 4
Questioning Research Methodology

Introduction

In this chapter I look at the research methodology underlying the studies discussed in the previous chapter. In particular, I explore the positions researchers took in relation to their subject and study participants, what research instruments, samples, and time frames they used, and lastly, how they analyzed their data.

Research Positions

Researchers studying the experiences of parents who have lost a baby to SIDS appear to approach the topic from one of two positions: they either assume an intimate physical and emotional connection with the parents or they remain remote from them, studying the experience both from a physical and emotional distance. The position researchers take affects the kind of information their studies can produce.

Bergman et al. (1969) were among the first researchers to ask what "psychiatric toll" (p. 99) SIDS took from surviving families. In other words, these researchers just wanted to learn what this experience was like so they could find a way to help. Since little information about this subject was available at the time, Bergman et al. chose to learn directly from the parents themselves. The authors met face-to-face with 225 families in their homes to listen and to learn. Lifton (1982) captures the essence of the approach taken by these researchers.

> There are certain kinds of suffering that we as professionals don't understand and don't know about. A certain humility before suffering is useful. ... [Those who have suffered] have been through things that [we] don't know about; [we've] never touched them; they know things [we] don't know. At our wisest as professionals, we really just listen and give them the sense that they understand something that we don't know (p. 226).

Bergman et al. (1969) did not attempt to systematically analyze their observations and interviews. They simply described the nature of the parents' experiences and the factors that seemed to be contributing to their overwhelmingly intense early grief. As I read this study, I could feel the researchers' humility and profound respect for the parents' pain. Studies by Cornwell et al. (1977) and Rubin (1985) communicate this same sense of respect and personal connection.

In contrast, other researchers assume a position of professional distance when they try to understand this experience. They stand outside of the parents' experience, their primary goal being to measure and categorize some aspect of the parents' grief. Although these researchers may ask many of the same questions as more intimate researchers (Bergman et al., 1969: Cornwell et al., 1977; Rubin, 1985), they study the experience from a distance instead of meeting parents face to face. One way they do that is to use questionnaires (DeFrain & Ernst, 1978; DeFrain et al., 1991; DeFrain et al., 1992; Nikolaisen & Williams, 1980; Price et al., 1985; Williams & Nikolaisen, 1982). These questionnaires are usually constructed after a review of the literature and, in some cases, a discussion with other professionals. Researchers then contact parents who have lost a baby to SIDS and whose names are on government and hospital lists to ask them to participate. If the parents agree, then they receive a lengthy questionnaire in the mail with instructions to complete it by themselves. Many questionnaires consist of numerous Likert–scale, multiple choice, and closed questions about some specific aspect of the grief experience.

DeFrain & Ernst (1978) justify the use of questionnaires to study parental grief for two reasons. First, they worry that interviews might interfere with the education and counselling services available to

families. I fail to see how participation in an interview might interfere with any intervention program. In fact, Lowman (1979) actually used parents from an intervention program to complete his study; both researcher and parents benefited. Raphael (1983) suggests that parents might benefit from even one interview, even it is for research purposes. It could be therapeutic for parents to share their grief with someone outside the family, perhaps for the first time.

The second reason DeFrain & Ernst (1978) give for using questionnaires is that they wanted to avoid upsetting parents. This justification disintegrates when one reads a written note from one of their participants. She describes what it was like to complete their 13–page questionnaire: "I would write and I would cry. Put it aside a few days, and then write a page, and cry. If an interviewer had come to my door, I'd have broken down completely" (p. 987). Completing this questionnaire upset this woman for several days. At least if she had been interviewed, she would not have cried alone or perhaps for so long. Meanwhile, the researchers remain in their office, awaiting her response so they can analyze it, safe from direct exposure to her suffering.

DeFrain et al. (1991) continue to use questionnaires for their research to this day despite the fact that parents keep taking the initiative to contact them, to try to get the opportunity to tell their stories in their own way.

> [The parents] call on the telephone to talk about their questions, their fears, their sadness. They invite us to meet with their family or their support group. They come forward after a presentation to tell their unique stories. ... These people, who have contacted us informally over the years, have each brought us insight into understanding the death of a baby. ... (p. x).

These parents seem to be inviting the researchers to enter their world of suffering, to stop standing outside it so they can intimately involved with the experience instead of looking at it from a distance. Maybe it is time that researchers responded to this invitation.

Research Instruments

The position researchers take towards their study influences the instruments they chose to use. The instruments then shape the kind of data that can be collected. As I have already mentioned many researchers use questionnaires. As they are used in the studies under review, questionnaires produce lists, measure attitudes and intensities of feelings, find out if certain experiences are common, allow comparisons, and look for associations between various aspects of the experience. Results often come in numbers: averages, scores, number of symptoms, and percentages. While this type of information can be useful, it often quantifies and divides the parents' experience into pieces instead of promoting any understanding of the whole picture. For example, it does not help me to know that "the mean score of the parents' expressed feelings was 19.6 with a possible score of 7 to 28" (Williams & Nikolaisen, 1982, p. 59). Without basing this information in some kind of context, it is meaningless. It is remote from the parents' experience.

When constructing their questionnaires, some researchers include a few "open–ended questions ... when a range of different responses [are] expected" (Williams & Nikolaisen, 1982, p. 57) or when they decide they want parents to add a few comments of their own (DeFrain et al., 1991; Price et al., 1985). After completing the lengthy questionnaires, some mothers send the researchers pages and pages of their own words, words that describe their experiences in great detail and with great emotion (DeFrain et al., 1991). The "pain and sorrow ... evident in [the parents'] responses" (p. 60) seems to surprise Williams & Nikolaisen (1982). Instead of understanding that perhaps the questionnaire method restricts the parents' ability to tell their story, Williams & Nikolaisen (1982) conclude that their questionnaire must have reached a "special group" of parents, parents who chose to participate because they needed "a cathartic outlet for their feelings" (p. 60). What these authors fail to understand is that their open ended

questions may have released the "pain and sorrow" that the other questions merely tried to categorize and measure.

Other researchers use both questionnaires and interviews or observations (Cornwell et al. ,1977; Dyregrov & Matthiesen, 1987a; Dyregrov & Matthiesen, 1987b; Lowman, 1979; Johnson–Soderberg, 1983; Rubin, 1981). The questionnaires detect some issues; the face to face contact with the parents provides the researchers with the opportunity to explore these issues in greater depth.

Other studies involve only face to face contact (Mandell & Wolfe, 1975; Mandell et al., 1980; Rubin, 1985). Most of these researchers went to the interviews with a list of questions about specific aspects of the parents' experience (pregnancy problems, fathers' experiences, and maternal attachment to the baby) instead of letting the parents decide how they wanted to deal with the topic. These studies contribute to the general store of information, but they still only present part of the picture. And without access to the total picture, we can never claim to truly understand this experience.

Research Samples

Once researchers choose their research position and instruments, they need study participants. Serious problems exist with some samples upon which SIDS–grief research has been based. There are problems with mixing SIDS parents with other bereaved parents and there are gender problems in the samples.

Some studies use heterogeneous samples of bereaved parents, ignoring the uniqueness of the SIDS–loss experience. The most blatant example can be found in the sample used by Videka–Sherman (1982).[10] This sample includes a total of 194 parents: 110 parents

[10] The problems with this study made me decide not to include it at all in the review of the literature. I mention it here because, despite the blatant problems, this study is frequently quoted.

who lost their child to sudden illnesses (57% of these were due to SIDS); 60 parents who lost a child to an illness like cancer or heart disease; and 24 parents whose children died violently. The results of various objective measures were averaged across all groups, thus ignoring the uniqueness of a sudden versus expected death, a natural death versus a violent death. Smialek (1978) also uses a heterogeneous sample. She observed parents who had come to the hospital because their baby had just died suddenly. Only 75% of these babies were eventually diagnosed as SIDS babies. The other 25% of the babies died of other natural causes, accidents, or "homicidal mechanisms" (p. 160). In her description of parental behaviour, Smialek makes no distinction between the behaviour of parents whose baby died of SIDS and those whose baby had been murdered, perhaps by their own hand. In view of the enormous guilt SIDS parents already feel, this is totally unacceptable research.

The other major problem with samples concerns gender issues. First, mothers are over-represented in studies that purport to be about both grieving mothers and fathers. For example, DeFrain et al.'s book (1991) about parental grief is based on a sample that is 83% female; the DeFrain et al. (1992) article on grandparent grief has about the same ratio. The Nikolaisen & Williams (1980) and Williams & Nikolaisen (1982) articles are based on a sample that is 69% female. Chartier (1987), who studies men's grief, says this problem is not unusual. Either men's experiences are ignored totally or when men do participate in studies, they make up only about a third of the total number of respondents.

The second problem is related to the first. Some authors acknowledge that their sample is so seriously skewed that they can only write about the maternal experience (See Price et al., 1985). But, many others ignore this fact and write as if they have collected information from both mothers and fathers in sufficient quantity to justify using the collective term "parents." For example, Lowman (1979) writes about "SIDS parents" (p. 674) but all of his information comes from mothers. Although DeFrain et al. (1991) admit that they have an overwhelmingly female sample, they bury this important fact on page 105 of their book.

> Most of the information in this study came from women who reported on their feelings and actions and on the feelings and actions of their spouses. As a result, our study is basically about women and their responses to the death of their child (p. 105).

The DeFrain et al. confession points to a third problem: the use of one person (usually the woman) to speak for and about another's experience with grief. The only time that this is appropriate is when the goal of the study is to compare people's perspectives - but then both sides of the story are still needed. This is not, however, the reason many authors use the words of one family member to speak for another. Lacking male participation in their study, some researchers encourage women to speak for men (Mandell et al., 1980) or for the couple (DeFrain et al., 1991; Price et al., 1985) or even for the whole family (DeFrain & Ernst, 1978; DeFrain et al, 1991). While it may be true that men seldom participate in studies, researchers should not expect women to speak for them. Although not directly a gender issue, researchers also ask mothers to describe their children's reactions to the baby's death (Cornwell et al., 1977; DeFrain & Ernst 1978; DeFrain et al., 1991; Price et al., 1985). No one thinks to ask the father about his children's behaviour or better still, no one thinks to interview and observe the children directly.

The last problem with sample selection is that few studies treat couples as the unit of analysis. Instead they compare groups of men to groups of women, even if the sample consists of married couples (Williams & Nikolaisen, 1982). Although Dyregrov & Matthiesen (1987a) do some within–couple comparisons, their study focuses mostly on gender comparisons. Although this study helps us learn about the similarities and differences between fathers' and mothers' grief, it does not help us learn how couples handle their differences within the bounds of their relationship. If this is our goal, then we must begin to include couples in our samples.

Research Period

Besides choosing the sample, researchers must also decide the period of time their study will cover. There are two issues here: over what period of time will the study itself take place and how long ago will the parents have suffered the death of their baby? Both decisions have important implications for what the researcher can learn about the parents' experience.

Although the death of a baby to SIDS may seem like a time-limited event to everyone outside the immediate family, it can feel like a neverending process to those inside the family. Many studies capture one or two pictures of this process, but these pictures are often frozen in time and have no context. This is a reflection of the use of single questionnaires or one-time interviews. In comparison, a longitudinal or retrospective study can capture changes in the parents' experience over time, changes in what they thought about why their baby died, having another baby, the health of their marriage, and their grief.

For example, Price et al. (1985) asked mothers to look back at their experiences and to compare how they felt just after the baby died and then six months later. This retrospective study shows the changes that occurred in the women's lives during a short time. Cornwell et al. (1977) met with parents shortly after the baby's death and then again three or four times over the first year. Their study has vitality, immediacy, and a recognition of the passage of time, even if it only covers one year. Rubin (1985) asked women about changes in their relationship with their deceased baby over time. By recognizing that grief is a process and that attitudes and feelings might change over time, these researchers were able to identify important issues that had gone unnoticed by researchers who had taken a narrower picture of the experience.

The second decision about time is connected to what researchers believe about how long it takes people to deal with a loss. If researchers believe that grief is time–limited and that grieving ceases within six months, then they will only concern themselves with the first six months of the experience (Lowman, 1979). If, however, they understand the neverendingness of the experience, then they are less likely to set such rigid time limits (Rubin, 1985). The more grief time a study covers, the more we can learn about how grief might change over time.

Analysis of Data

My most serious criticism concerning data analysis has to do with research bias. There is a growing concern that "the measurement of grief itself is biased because of gender stereotypes" (Stinson, Lasker, Lohmann, & Toedter, 1992, p. 218). This position is shared by Chartier (1987) who says that much of the information about how people grieve is based on the study of widows. Cook (1988) concurs. She suggests that the study of "parental mourning may be shaped by a tendency to apply and operationalize concepts formulated through the study of grieving **mothers** rather than **fathers** [emphasis in original]" (p. 287). Without questioning the source of the concepts and the gender of the study participants, researchers and counsellors alike have accepted that talking and crying are the right and healthy ways to grieve. Anything different seems to be considered wrong and unhealthy. This makes some grievers, mostly men, appear deviant and in need of help.

For example, Mandell et al. (1980) found that grieving fathers coped with their baby's death by increasing their time at work, avoiding professional support, wanting another baby, and intellectualizing and explaining away their feelings. The authors (and the men's wives) say that these behaviours mean that the men are denying their experience; they are not working on their grief. The use of the term "denial" (p. 222) suggests that Mandell et al. believe that grief work must always involve talking and crying. Cook (1988) found the same kinds of

behaviours in the grieving fathers she interviewed. In her view, however, these behaviours are entirely appropriate and understandable, given the social pressure for men to be strong and to control their emotions in the midst of a crisis. We need to keep our eyes open for gender bias in the analysis of parental grief studies. It colours most of the work in this area.

Beyond the gender bias, I have two other major concerns about data analysis. The first issue is what researchers consider usable data. A few studies seem to value the experience of the parents only for the statistics they create. For example, Mandell & Wolfe (1975) interviewed 32 mothers who had lost a baby to SIDS and who wanted to have another baby. Many of these women had difficulties conceiving or carrying a subsequent pregnancy to term. Mandell & Wolfe report only the ratio of women who had problems. Although the researchers interviewed women about their problems, nothing from the interviews is included in the article. It is as if the women's words do not count.

Other studies use the parents' words but not for research purposes. The researchers do not treat the parents written and spoken words as usable research data. Instead they scatter a few quotes throughout their article to illustrate a point or to flesh out their statistical analysis (Dyregrov & Matthiesen, 1987a, 1987b; Williams & Nikolaisen, 1982).

Even those who seem to value the parents' experiences do not analyze what the parents send to them (DeFrain et al., 1991) or say to them during interviews (Cornwell et al., 1977). Although Rubin (1981, 1985) does a masterful job of presenting information about maternal attachments to the deceased child, he does not explain what method of analysis he used to form his conclusions. This kind of approach creates a negative attitude toward qualitative research. It makes it look as if this kind of research involves nothing more complicated than writing down other people's stories.

Conclusion

This concludes my critique of the research methodology used by researchers to examine the aftermath of SIDS. Along the way I discovered problems with the positions taken by some researchers, and difficulties with research instruments, samples, time periods, and the analysis of data. These problems indicate the need for the adoption of a more personal and comprehensive methodology, one that allows the parents to teach researchers about their experience. In the next and concluding chapter I apply what I have learned from my critique by developing a set of new research questions and proposing the use of an appropriate research methodology to answer them.

Chapter 5
Responding to the Questions: Recommendations for Future Research

Research Questions

My review and critique of the available research about parental grief following the death of a baby to SIDS leads me to conclude that we still have much to learn about the nature of this tragic experience. Rather than reiterate what I have already said about the issues that require further investigation, I have collapsed them into six topical questions.

- What do parents do to make the transition from being overwhelmed by their grief to living a "normal life" again (Cornwell et al., 1977, p. 658)?

- What is the connection between the lack of a medical explanation for the baby's death, the parents' own explanation for the death, and the way parents grieve?

- What is the connection between gender and the way parents deal with both their grief and their continued relationship with their deceased baby?

- What do parents do to handle their grief within the context of their marital relationship?

- What do parents do to handle their grief within the context of their relationship with their already-born and still-to-be-born children?

- What is the grief trajectory like, that is, how does grief change over time?

All of these questions can be subsumed under one general question: **What is it like to lose a baby to SIDS?** Because of the nature of the topic, this question can best be answered by conducting face-to-face interviews with parents who have had this experience. They can become our teachers. But first, we need to discuss the research methodology guiding such a study.

Recommended Research Methodology

Theoretical perspective

The most appropriate theoretical perspective for a study of this nature is symbolic interactionism. This social psychological theory focuses on the changing and interacting nature of the individual, society, mind, self, and truth (Charon, 1979). According to this theory, people are always in process of becoming rather than being a finished product. Symbolic interactionists believe that the self and society are so embedded in one another that neither can stand alone.

According to this theory, the self is composed of two abstract parts: the "I" and the "Me." The "I" is the "immediate, spontaneous, and impulsive aspect of conduct" (Hewitt, 1984, p. 72). It is the doing part of the self, the part that acts on the spur of the moment. It feels emotions intensely, spontaneously, and is subjective in nature. The "Me" is the more objective and socialized part of the self. It observes and assesses "I"'s actions and compares them to internalized standards and beliefs. This part of the self manages the expression of emotions. The "Me" also allows a person to take the role of the other, that is, to see oneself as others might. This is the way in which society is embedded in the individual's consciousness. The "I" and "Me" continually interact so that the self is always in process.

When people feel at ease with themselves and interactions within their world, the two parts of the self feel "fused" (Scheff, 1985, p. 258). The self is in balance. This balance, and therefore one's sense of self, however, is precarious. Balance may be lost temporarily in times of crisis when previously held perceptions or definitions of reality, self, or others no longer fit the situation.

According to symbolic interactionists, people's "realities are [their] definitions of situations" (Charon, 1979, p. 136) and they act according to their definitions. Through their interactions, people continually define and redefine the meanings of objects, ideas, and other people. They even define and evaluate their own thoughts, feelings, and actions (Blumer, 1969). These definitions are fluid and subjective. In social encounters, people continually observe themselves and others so that they can define the situation. Then they organize their behaviour according to their definitions (Goffman, 1959). As long as definitions are shared, interactions run smoothly; the social world gives off the appearance of structure and order. People think their world is safe, predictable, and, to some degree, controlled by logical forces. When this apparent structure is disturbed somehow, interactions cannot run smoothly because people feel lost and confused. They do not know how to act, what to expect from others, or even what to expect from themselves.

One disturbing experience that is likely to cause severe confusion is the death of a loved one. Rosenblatt (1988) asserts that

> a significant loss is, among other things, a loss of reality. [Symbolic interactionism] helps us understand how important others are in defining a loss, feeling the loss, and coming to terms with it" (pp. 67-68).

When confronted with a loss, the bereaved look "for structure, and where [they] do not find it, [they try to] create it" (Hewitt, 1984, p. 79). Until that sense of order and meaning is restored, people feel uncomfortable and alone. They may question their most basic assumptions about life, g als, and relationships. Because symbolic interactionism recognizes people's continuous efforts to define meanings

when they are in crisis, it is an appropriate theoretical perspective to use for the study of parental grief after losing a baby to SIDS.

Research method

According to Blumer (1969), if we wish to understand a group of people, then we must "lift the veils that obscure or hide what is going on" (p. 39) within that group. This can be accomplished by being with and observing the people we want to understand so that we can gradually begin to see the world through their eyes. Blumer calls this stage: exploration, or "the direct examination of the actual empirical social world" (p. 48). To go beyond mere description to a deeper, more theoretical level of understanding, Blumer says we must move to the next level: inspection. The goal of inspection is to pose the research problem in theoretical terms, uncover common categories of experience, define relevant concepts, and, lastly, put forth theoretical propositions. Inspection allows the researcher to go beyond the specific and obvious experiences of a group of people and to move to an examination of the assumptions and beliefs underlying the experience under consideration. Blumer's inspection uses methods similar to those found in grounded theory.

Like inspection, the purpose of grounded theory is to "generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved" (Glaser, 1978, p. 93). The grounded theory method is closely aligned with symbolic interactionism. It is based on the assumption that people continually define and redefine the meaning of their experiences to achieve some sense of order and structure in their lives (Hutchinson, 1986).

To build theory using this method, there must be a continuous "interaction between the researcher and the phenomenon under study" (Field and Morse, 1985, p. 111). In other words, the researcher becomes intimately involved with the subject matter and with the study's subjects. Unlike purely deductive research methods that develop theories in the abstract, grounded theory begins with the experiences

of the people. Then, using a systematic set of procedures to understand people's stories and the researcher's observations, the researcher inductively develops a theory about how people deal with the situation under study.

In closing, I recommend the use of grounded theory to study what it is like for parents to lose a baby to SIDS. It allows the parents to talk about their experiences in their own words and in their way. It brings the researcher into direct and intimate contact with the parents who are living the experience. Lastly, it provides a systematic method of analyzing the data so that the study goes beyond mere description. Since the researcher becomes the research instrument, this kind of research requires someone who is willing to immerse him/herself in the experience. Is anyone ready to take on the challenge?

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